Research Plus+

Contemporary Social Issues and Business Research

Parents/Carers of Substance Misusers Research and Development Project

Findings From The Research

Prepared for Norfolk Crossroads and the Norfolk DAAT

August 2005

Contents

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Executive Summary

E1. Introduction

- This report presents the findings of research on substance misuse carers in Norfolk. The research was commissioned by the Norfolk DAAT (Drug and Alcohol Action Team) as part of a research and development project carried out jointly with Norfolk Crossroads – Caring for Carers.
- The research was undertaken between January and July 2005.
- The purpose of the project, as described in the tender document, was 'to gain an understanding of the needs and support available for parent/carers, including young carers and affected others, who are caring for those who are substance misusing'.

E2. The research methodology

- The research addressed Part 1 of the project specification:
  - To map current provision across the county for carers of substance misusers
  - To identify areas of unmet need for this group
  - To identify the profiles of hidden carers across Norfolk.
- The research consisted of:
  - The collection and examination of background information
  - An email survey of local agencies
  - Individual interviews and a focus group with a sample of carers of substance misusers – 20 adult carers and six young carers participated in the research.
  - In addition two profiles of adult carers and seven profiles of young carers were developed.

E3. Background to the research

- Over the last fifteen years, the needs of carers in general have been increasingly recognised. New legislation, strategies and guidance for carers, including substance misuse carers, have been introduced.
- A wide range of reports relating to the needs of and services for substance misuse carers have been published in the last five years.
- As part of the research, some national organisations and helplines were contacted to determine what provision is available nationally for substance misuse carers.
- Information was obtained on local agencies that provide support to substance misuse carers in other parts of the UK. These provide potential models for services in Norfolk.
- Initiatives for carers in Norfolk were also identified.
- All of these highlighted a wide range of issues affecting substance misuse carers.

E4. Sources of support for carers of substance misusers – findings from the survey of agencies

- In total, 31 completed questionnaires were returned from 28 agencies in relation to support for adult substance misuse carers in Norfolk. The response rate was 61%.
- Half of the agencies did not identify any 'national or local standards or protocols' that they worked to.
- Others mentioned a wide range including the Norfolk DAAT guidelines, national QUADS standards (Quality in Alcohol and Drug Services), the internationally established 12 step pattern, local ACPC protocols (Area Child Protection Committee) and the Adfam standards, which were about to be published.

Confidentiality, data protection and risk assessment procedures were also mentioned.

- There appeared to be little specific funding for carers of substance misusers and what was available was not established on a long term basis.
- The Carers Grant appeared to be primarily used by the general carers' agencies, which did not work with many substance misuse carers.
- Only six agencies were aware of any national or local research or reports on the needs of substance misuse carers.
- The agencies provided a wealth of information on the main issues faced by substance misuse carers, the effects of substance misuse on carers and the barriers to providing support to substance misuse carers. Many of the issues mentioned reflected the issues identified in national research, as outlined in Section Three.
- A third of the agencies indicated that they were aware that substance misuse carers are entitled to a Carers Assessment.
- Eighteen agencies identified gaps in current service provision. A number of agencies did not feel well enough informed to comment on this.
- Gaps identified included: carers' lack of awareness of entitlement to services, a need for support services that are dedicated to substance misuse carers, ring fenced funding for substance misuse carers, culturally specific services, a need for more therapy and more respite care.
- Suggestions to improve services related to the gaps were identified. They included more publicity aimed at carers, more specific and secure funding, more respite care, more trained staff and a change of public perceptions of what it means to be a substance misuse carer.
- Two thirds of the agencies had little or no awareness of other agencies or sources of support for substance misuse carers.
- Based on the responses to the questionnaire, telephone calls to agencies that did not respond and other information obtained during the course of the research, the support services available to substance misuse carers in Norfolk were summarised.
- It was concluded that the main sources of sustained support are the Linking Together Project in West Norfolk, NORCAS, the Matthew Project, and the self help support groups. There are seven Al-Anon Family Groups across the county for carers of people with alcohol problems but only three Families Anonymous groups for carers of people with drug problems. In cases of dual diagnosis, some of the support services for mental health carers also provide support to substance misuse carers. However the emphasis is usually on the mental health issues.

E5. The adult carers and their substance misusers

- Twenty adult carers were interviewed.
- The characteristics of the carers interviewed reflect those carers who were willing to come forward to participate in the research, rather than being a representative sample of all substance misuse carers in Norfolk. In particular, the age range of the carers may not be representative of carers of substance misusers.
- However the carers, and those whom they cared for, did represent a range of socio-economic groups living in different circumstances across most of Norfolk. The carers included parents, siblings and grandparents of substance misusers. The substance misusers encompassed those with drugs and/or alcohol problems and people at different stages in their substance misuse / recovery.

- Some of the carers interviewed were able to reflect on what it had been like when they had been providing more intense care, whilst others were in the midst of caring at the time of the research.
- The carers reported that the substance misusers had experienced a wide variety of problems related to their substance misuse. This demonstrated that the carers were facing complex problems.
- Over 80% of the substance misusers were reported to have had problems with their emotional / mental health, relationships, crime, money / debts and/or employment.
- A smaller, but significant, proportion were reported to have had problems related to their physical health, education, housing and/or been involved with the criminal justice system, including time spent in prison.
- In addition, two substance misusers had been involved with social services in relation to the care of their children and two had been involved in sex work.
- Although none of the carers interviewed had current substance misuse problems themselves, in some cases there was evidence of a family history of substance misuse. This was not restricted to those living in socially disadvantaged areas.

E6. Caring for substance misusers

- Some of the carers had been caring for the substance misuser for many years, a quarter of them for ten years or more.
- The carer was not currently living with the substance misuser in 45% of cases.
- The carers described a wide range of care and support that they provided to the substance misuser, due to their use of drugs and / or alcohol. The key activities mentioned were providing emotional support and being there to help the substance misuser.
- This included providing money and financial support, providing domestic support to those living with them (washing, cooking, cleaning), doing or helping with shopping and providing food or meals for those not living with them, making appointments and accompanying them to appointments. Other activities included: monitoring their medical needs, supervising their medication, providing housing, providing transport, taking them out and dealing with letters.
- The carers identified the main problems experienced by carers of substance misusers. They referred to the emotions they had to deal with as well as practical issues. These included stress, fear, isolation, frustration and anger, difficulties with obtaining information and support, issues related to confidentiality and financial worries.
- Half of the carers said that they saw themselves as ‘a carer’,
- The carers reported on how the person’s substance misuse had affected their life:
  - 90% or more of the carers reported that the person’s substance misuse had affected their relationship with their partner, their emotional / mental health and their financial position. Based on the ‘social malaise inventory’ (Rutter et al., 1981), half of the carers had a ‘marked’ or ‘high’ emotional stress level.
  - Over 60% of the carers reported that the person’s substance misuse had affected their relationship with other family members, their physical health, their employment or employment plans and their social life.
  - Over half reported that it had affected their plans or wishes for future employment and for a third it had affected their studies or plans for study.
- When the carers were asked what had been the hardest thing to cope with, the main thing they mentioned was the loss of control and worry about what would happen to the substance misuser. Other challenges included: not knowing what to do for the best and the frustration of not being able to obtain help for the

substance misuser when there were both mental health and substance misuse problems.

- When asked how well they felt they had coped with the person's substance misuse, there was a varied response. Some thought that they had coped well, many felt that they had dealt with the situation better over time and some felt that they had not coped well at all.
- The carers reported on how the person's substance misuse had affected the life of other family members:
  - Over 80% of the carers reported that the person's substance misuse had affected the emotional / mental health of other family members.
  - Over 60% reported that it had affected the personal relationships and the social life of other family members.
  - Over half reported that it had affected the physical health of other family members and a third reported that it had affected the financial position of other family members.
  - Over a quarter reported that it had affected the studies, or plans for study, of other family members.
  - Over a fifth reported that it had affected the employment, or the employment plans, of other family members.
- When asked how well other family members had coped with the substance misuse, the carers' responses were fairly evenly split between those who felt that other family members had coped well and those who felt that other family members had found it difficult to cope. The responses also revealed that in some cases the carer had mainly coped on their own, as either other family members had not really been involved or because the carer had shielded them from the situation.

E7. Sources of help and support used by carers

- All but one carer said that they had contacted someone for help and support.
- In 20% of cases the carers had contacted someone within six months of starting to provide support to the substance misuser, a quarter had contacted someone between two and ten years. Approaching a third had not contacted anyone for help and support for over ten years, in some cases much longer.
- Overall, 80% had received some form of help and support.
- The carers were asked whether they had ever sought help and support from seventeen specific types of agencies. The key agencies contacted were their own GP, the substance misuser's GP and the police.
- None of the carers reported that a GP had talked to them about being on a carers' register or joining a carers group.
- At least half had contacted a mental health worker (either for themselves or the substance misuser), a self help / support group, an alcohol or drug project, a community or voluntary project or a telephone helpline.
- Other sources of help and support were: a church or religious centre, a solicitor, social services or a social worker, other workers at a GP surgery, other health workers, the CAB and probation.
- None of the carers had contacted a carers' organisation for help and support.
- When asked to identify up to three of the agencies that had been the most helpful to them, 40% of the carers identified a self help / support group.
- A fifth of the carers identified their own GP, the substance misuser's GP, a mental health worker, a community or voluntary project or a solicitor.
- 45% of the carers identified some people or places that they personally would <u>not</u> really want to go to for help.

- Three of the carers had been offered a carers' assessment, but only one had actually had one.
- 65% of the carers said that they would like more help and support.
- The carers' suggestions to improve support to carers included more information about the substance misuse and treatment, information about sources of support for themselves and more support services.
- In many cases, the carers viewed the provision of support to the substance misusers as a key source of help to themselves.

E8. Consultation and involvement

- 75% of the carers said that they would like to be consulted or involved in the services provided for the substance misuser they cared for.
- 70% of the carers said that they would like to be consulted or involved in the services provided for substance misusers in general.
- Some carers commented that they were very keen to be involved, whilst others queried the appropriateness of involvement with services for substance misusers.
- 80% of the carers said that they would like to be consulted or involved in the services provided for substance misuse carers.
- 90% of the carers said that they wanted to be invited to the conference following this research.

E9 Young carers

- There are 25 young carers groups across Norfolk.
- Eleven completed questionnaires were returned from 19 young carer groups. A response rate of 58%.
- The Carers Grant was an important source of funding for the young carer groups and all agencies that apply for a Carers Grant have to work to agreed standards.
- Eight of the agencies did not identify any 'national or local standards or protocols' that they worked to.
- Only one agency was aware of any local or national research or reports on the needs of young carers of substance misusers.
- The agencies provided considerable information on the main issues faced by young carers of substance misusers and the barriers to providing support to them. Many of the issues mentioned reflected the issues identified in national research, as outlined in Section Three.
- All but three agencies identified gaps in current service provision and made suggestions to improve services for young carers.
- Four of the agencies were not aware of any other agencies that provided support to young carers of substance misusers.
- Six people, who were, or had been, young carers, provided information on their experiences. These included:
  - The extra domestic responsibilities they had to take on, including care of their siblings and the substance misuser
  - Other effects of substance misuse in the home
  - The effect on their physical and emotional health, their education, friendships and sexual safety
  - The potential for inter-generational substance misuse.
- The young carers identified sources of support and which agencies they would not wish to contact.
- A statement by a young carer and seven profiles of young carers, illustrated in more detail the issues facing young carers in Norfolk.

E10 Conclusions and recommendations

Conclusions and recommendations are made in relation to:

- Carers' initial information needs
- Carers' assessments
- Carers' support and training needs
- Direct funding to adult substance misuse carers
- Funding for agencies that work with adult substance misuse carers
- Primary care services
- GP Carers' Registers
- Carers' relationship with agencies treating the substance misusers
- Mental health issues and dual diagnosis
- Good practice standards
- Information and training for agencies
- Hard to engage groups
- Carer consultation and involvement
- Young Carers
- Substance misuse carers who work for substance misuse or carer agencies.

It is also recommended that: A three to five year Action Plan is drawn up to implement the recommendations, with a built in annual review process.

Section One
Introduction

1.1 Introduction

This report presents the findings of research on substance misuse carers in Norfolk. The research was commissioned by the Norfolk DAAT (Drug and Alcohol Action Team) as part of a research and development project carried out jointly with Norfolk Crossroads – Caring for Carers. The research was undertaken between January and July 2005.

1.2 The Aims and Objectives of the Project

The purpose of the project, as described in the tender document, was 'to gain an understanding of the needs and support available for parent/carers, including young carers and affected others, who are caring for those who are substance misusing'.

The aims and objectives of the project, as described in the tender document consisted of two parts:
'Part 1

- To map current provision across the county for carers of substance misusers
- To identify areas of unmet need for this group
- To identify the profiles of hidden carers across Norfolk.

Part 2

- To assist in the development of new services across the county
- To design a multi-agency protocol to promote effective carer representation and participation in service development/monitoring forums.

Overall the project also needed:

- To network with other agencies and posts that have a similar remit
- To assist and help develop the information needs of carers and to ensure a link to the DAAT Information Group.'

1.3. Definition of a carer

The government carers' website provides a very broad definition of 'carers'. They are:
'People who look after a relative or friend who needs support because of age, physical or learning disability or illness, including mental illness'.

The government carers' website also defines young carers as follows:
'Carers who are under the age of 18. The person receiving care is often a parent but can be a brother or sister, grandparent or other relative who needs support.' (see www.carers.gov.uk).

The Norfolk Carers' Action Plan 2003 – 2006 defines the term 'carer' as:
'Someone of any age who provides unpaid help and support to a relative, friend, partner or child, who cannot manage because of illness, age or a disability.' (Norfolk Carers Partnership of Norfolk County Council, Norfolk Health, Carers, Voluntary Agencies and the Department of Work and Pensions, 2004).

For the purposes of this research the following definition of ‘a carer’, adapted from the above definitions, was used:
‘A carer is someone of any age who provides unpaid help and support to a relative, friend, partner or child, who needs support because they have problems related to substance misuse’.

For the purposes of this research the definition of ‘a young carer’ was:
‘A carer aged up to 18 years’.

Where ‘a carer’ or ‘carers’ are mentioned in this report, this refers to ‘parents and carers’ of substance misusers. Many individuals providing support to substance misusers do not see themselves as carers. Increasingly organisations do not use the term carer and prefer to use the phrase ‘looking after someone’.

1.4 Format of the report

The format of the report is as follows:

- Section Two describes the research methodology.
- Section Three provides an overview of the national and local context for the research.
- Section Four provides an overview of services to support carers and families of adult substance misusers in Norfolk, based on the survey of agencies. It also maps the links between services and the standards and protocols that they work to.
- Section Five provides a description of the carers interviewed for the research and the substance misusers they cared for, including problems arising from their substance misuse and any family history of substance misuse.
- Section Six explores the impact of the substance misuse on the carers and their families.
- Section Seven explores the sources of support used by carers and their suggestions to improve them.
- Section Eight addresses issues of consultation and involvement of carers.
- Section Nine explores the needs of and services available for young carers.
- Section Ten presents the conclusions and recommendations.

The report also includes two profiles of adult carers and seven profiles of young carers.

A glossary of abbreviations is provided at the end of the main report, after the references.

Section Two
The Research Methodology

2.1 Introduction
This section describes the research design and how the research was carried out.

2.2 The research design
The research addressed Part 1 of the project specification:
- To map current provision across the county for carers of substance misusers
- To identify areas of unmet need for this group
- To identify the profiles of hidden carers across Norfolk.

In undertaking the research it also contributed to the following other aspects of the project specification:
- To network with other agencies and posts that have a similar remit
- To assist and help develop the information needs of carers and to ensure a link to the DAAT Information Group.

The research consisted of:
- The collection and examination of background information
- An email survey of local agencies
- Individual interviews and a focus group with a sample of substance misuse carers.

These are described in more detail below.

2.2.1 Background information
Information from national and local research, reports and policy documents on the needs of carers of substance misusers were examined. National organisations working with substance misusers or carers were contacted for information about their activities. Some information from relevant projects in other parts of the UK was obtained. Initiatives to support carers in Norfolk were identified.

2.2.2 Email survey of local agencies
An email survey was carried out with local agencies that work with the carers of substance misusers in Norfolk or who might be aware of their needs. Agencies were first contacted by telephone to find out whether they worked with carers of substance misusers and/or were aware of their needs. Those that did were then sent a self completion questionnaire by email and / or post. The main agencies contacted were:
- The main Norfolk carer agencies
- The Norfolk Young Carers projects
- The Norfolk drug and alcohol agencies listed in the ‘Drug and Alcohol Services in Norfolk’ booklet, who stated that they worked with carers of substance misusers
- Some of the Norfolk drug and alcohol agencies, who did not state whether they worked with carers of substance misusers
- The substance misuse social workers, who work with the drug and alcohol agencies
- Some mental health agencies.

The aim was to obtain at least 25 completed questionnaires from agencies in Norfolk. A total of 65 agencies were sent a questionnaire, following telephone contact to check whether it was appropriate for them to complete a questionnaire. Some of the

agencies did not respond within the three week deadline, some did not respond for over two months and some did not respond at all. This held up the research, as their responses were going to be used to guide the content of the interviews / focus groups with the carers.

A total of 42 questionnaires were completed. Nineteen of the questionnaires were sent to young carers projects. Eleven out of 19 questionnaires were returned, a response rate of 58%. The remaining 46 were to other agencies. Out of 46 questionnaires, 31 completed questionnaires were received. Some agencies were sent one questionnaire but it was completed by a number of their staff. A total of 28 agencies completed questionnaires, a response rate of 61%. A list of the organisations that completed the questionnaire is provided in Appendix 1.

Some of the respondents from the agencies were also carers themselves, sometimes for someone with a substance misuse problem. They were able to contribute to the research as both a professional and as a substance misuse carer.

2.2.3 Interviews / focus groups with substance misuse carers

It was considered essential to include the views and experiences of the carers of substance misusers themselves. A number of methods for doing this were considered. It was concluded that there was a need to be flexible. The agencies contacted as part of the email survey were asked for advice on how to approach carers and whether they could assist with finding carers to participate in the research. It was envisaged that about twenty people would be interviewed. Some of them could participate as part of a focus group and others would be interviewed individually, depending on their circumstances. In practice most people expressed a preference to be interviewed individually. Twenty adult carers were interviewed.

People found out about the research through a variety of routes. Most came through contact with agencies, including Rethink, the NELM Community Support Team, Linking Together, NORCAS, carers agencies and a Mental Health Support Team. Others saw the poster in the library and one person was referred by another interviewee.

A number of other people were also willing to be interviewed. Several of these were people who were carers and were also working for organisations who provided support to carers. Whilst it was important to include their views, it was felt that they should not dominate the sample of people who were interviewed. Towards the end of the research, there was an opportunity to interview a man with an alcoholic wife, but his son, a young carer, was interviewed instead.

Finding the young carers was more of a challenge. Many of the young carers projects said that they did not currently have any young carers of a substance misuser or did not know if the young carers they were working with were caring for a substance misuser. The challenge of finding young carers was overcome by using a variety of approaches:

- With the help of the young carer projects a small focus group was arranged, which four young people attended.
- Two people, who had been carers when they were younger, were interviewed. They were now able to look back and reflect on their caring role. Both of them had looked after alcoholic mothers, one of whom had long standing mental health problems.

- One adult carer of a substance misuser had also been a young carer of a substance misuser, and provided some information on this.
- Seven profiles of young carers were developed. Most of these were based on information provided by the young carers project workers.
- A small amount of data was reused from another research project that Research Plus+ carried out in the previous 12 months.
- Crossroads Caring for Carers provided some information written by a young carer.

The individual interviews with adults and young people and the focus group explored people's views on the challenges faced by the carers of substance misusers, the assistance and support they had received and their ideas to improve the services and support available. As some of the participants might be vulnerable young people or vulnerable adults, particular attention was paid to issues of informed consent and confidentiality. A thank you voucher for £10 was given to each person who participated in a focus group or was interviewed.

At the end of the focus groups / interviews with carers, they were offered information that might be helpful to them – the 'Who Cares?' booklet, information about the 'Carers Voice' from Norfolk County Council Social Services and the 'Drug and Alcohol Services in Norfolk' booklet.

The formal interviews were recorded and/or notes were taken. The interviews were then written up in note form and, in most cases, were sent back to the interviewees to verify them for accuracy etc. The focus group was recorded and notes were taken on a flip chart. The focus group was then written up in note form and did not identify individuals.

2.3 Analysis and interpretation of the data

The statistical data was collated and analysed using SPSS, a computer package for the analysis of statistical data. The textual / qualitative data from the research was collated and analysed manually.

Section Three
Background to the Research

3.1 Introduction
This section presents information on national and local policy, research, reports and documents on the needs of carers of substance misusers. It also provides an overview of national organisations for substance misuse carers, some information on local projects in other parts of the UK and details of initiatives for carers in Norfolk.

3.2 Recognition of carers and their needs
Over the last fifteen years, the needs of carers in general have been increasingly recognised. New legislation, strategies and guidance for carers, including substance misuse carers, have been introduced.

3.2.1 Recognition of carers in general
The Carers Impact programme 1996 – 1999 was a national development programme working to improve support to carers in general (Banks and Cheeseman 1999, Banks 1999 and Carers Impact 1999). It developed a Carers Compass as an audit and performance tool to assist partnership working to meet the needs of carers. It is based on the premise that 'carers want a good quality of life for the person they care for and control of their own life' The Compass presented eight things needed to achieve this:

- Full information
- Recognition of their own health and well-being taken into account
- A life of their own – quality services for the carer and the person cared for
- Time off
- Emotional support
- Training and support to care
- Financial security
- A voice.

The NHS and Community Care Act 1990 required local authorities to take into account the needs of carers when undertaking assessments of the person they cared for and the Carers (Recognition and Services) Act 1995 turned this requirement into a duty. Carers were given the right to an assessment of their ability to provide care to the person they looked after when the needs of the person they cared for were being considered. However there was no legal requirement for local authorities to actually provide any services directly for carers.

In the following years, carers' needs were further recognised. In February 1999 the Government published 'Caring about Carers – a National Strategy for Carers' (Department of Health 1999a). The Carers' Strategy, as it is commonly known, recognised that carers provide a vital role but their needs were not being met as well as they should be. The strategy identified the main things that carers wanted were:

- Well-being of the person being cared for
- Freedom to have a life of their own
- Maintaining their own health
- Confidence in services
- A say in service provision.

The Strategy recognised that carers experienced higher than average levels of stress and reported on research evidence which suggested that things that help carers to cope and to continue to care, include:

- Time off from caring
- Relief from isolation, and satisfaction with the help they receive from their family and others
- Receipt of reliable and satisfactory services
- Information
- Recognition of their role and contribution.

The strategy referred to young carers looking after other family members with a drug or alcohol problem. Adult substance misuse carers were not specifically mentioned. However, it is now generally recognised the strategy does apply to adult, as well as young, substance misuse carers.

For substance misuse carers, where the substance misuser also has severe and enduring mental health problems, there has been further recognition of their needs. The National Service Framework for Mental Health (Department of Health 1999b) set out seven national standards for mental health for adults aged 16 to 65 years. Standard Six formally recognised the needs of carers of people with mental health problems:

'Carers play a vital role in helping to look after service users of mental health services, particularly those with severe mental illness. Providing help, advice and services to carers can be one of the best ways of helping people with mental health problems. While caring can be rewarding, the strains and responsibilities of caring can also have an impact on carers' own mental and physical health, and these needs must also be addressed by health and social services.'

(Department of Health 1999b, page 69)

The Framework stated that:

'All carers who provide regular and substantial care for a person on a CPA [Care Programme Approach] should:

- Have an assessment of their caring, physical and mental health needs, repeated on an annual basis
- Have their own written care plan which is given to them and implemented in discussion with them.' (Department of Health 1999b, page 69)

More recently, the Department of Health has issued some guidance on developing services for carers and families of people with a mental illness (Department of Health, 2002a).

It is now generally recognised that carers in general experience higher than average levels of stress than the general population and that they have needs in their own right as well as in relation to the person that they care for. Carers have been identified as a group that is at high risk of suffering mental health problems and should therefore be a target group for mental health promotion work, as set out in Standard One of the National Service Framework for Mental Health (Department of Health, 1999b). A review of effectiveness in mental health promotion (NHS Centre for Reviews and Dissemination, 1997) concluded that the 'mental health problems often experienced by long term carers can be prevented by respite care and some forms of psycho-social support.'

The introduction of carers' assessments and the provision of respite care have received particular attention by and specific guidance from the government. The

Carers Strategy introduced a grant for the enhancement of services to allow carers to take a break from caring. Using the Special Carers Grant local authorities could provide services to users, which indirectly provided a break for carers. However these were not without their limitations. The Special Carers Grant initially provided services to the service user to provide a break to the carer, who could not receive services directly. Some users were not eligible for this grant as the informal care they received was not within the local interpretation of 'sustained and regular'.

The Carers and Disabled Children Act 2000, which came into operation on 1st April 2001, extended the circumstances under which carers could receive an assessment and the opportunities for getting a break. Carers aged 16 and over, who provided, or were intending to provide, substantial care to someone aged 18 or over, who was eligible for community care services, were given the right to request an assessment of their needs. Carers could now be assessed even if the user was not assessed. The new act gave local authorities the power to provide services directly to carers. These services were not defined in the act but the Department of Health summary of the Act (Department of Health 2001a) stated that they could provide any service that either 'supports the carer in their caring role or helps the carer to maintain their own health and well-being' (page 7). It also stated that local authorities should 'listen to carers and be innovative in the type of support they offer'. In line with charging users for services, the Act enabled local authorities to charge carers for services too.

The Local Authority Circular on community care assessments (Department of Health, 2004a) re-stated the importance of fully involving individuals and their carers in the assessment and care planning for the individual and also the entitlement of the carer to request an assessment of their own needs in supporting the person they cared for. The Circular also stated that:
'Local authorities should continue to ensure that up to date and appropriate information on the range of support, entitlements and assistance available for carers is accessible in a variety of formats. This information should be offered to all carers, irrespective of whether a carer receives an assessment' (paragraph 2.6).

The Carers (Equal Opportunities) Act 2004 further extended the rights of carers. It stated that:

- The local authority has a duty to tell carers they identify that they may be entitled to a carer's assessment (unless the cared for person has already been assessed under Section 4 (3) of the Community Care (Delayed Discharges etc) Act 2003) in relation to the person they care for.
- The carer's assessment must include consideration of whether the carer works or wishes to work, or is undertaking, or wants to undertake, education, training or a leisure activity.
- Other authorities are required to give 'due consideration' to requests for help from a local authority in planning the provision of services that might help carers to continue to care. The 'other authorities' include any other local authority, any local education or housing authority or any special health authority, primary care trust or other health trust. This could apply when services for groups of carers are being planned or when an individual carer's needs are being assessed.

3.2.2 Registers of carers

'Modernising Health and Social Services' required primary care and social services authorities to set up systems for identifying carers of their patients / people on their caseloads. (Department of Health, 1998a, section on 'Promoting Independence'). The original target date for this was April 2002.

The update of the Quality and Outcomes Framework for the General Medical Services (GMS) Contract 2004 (Department of Health, 2004b) sets out how GP practices are to be assessed and rewarded for the quality of their clinical and organisational performance. The identification of carers for assessments is included in the Organisational Indicators on Practice Management. Indicator 9 states:
'The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment'.

The practice can be awarded three points for doing this, out of a total of 1,050 possible points.

3.2.3 Consultation and involvement of carers

The principle of consulting with and involving carers in the planning and provision of services to the people that they care for and themselves has been encouraged for many years and has gradually gathered momentum. There are now many examples of government documents, which promote the involvement of carers (see for example: Department of Health, 1997, Department of Health, 1998a, Department of Health, 1998b, Department of Health, 1998c, Department of Health, 1999a, Department of Health, 1999b, Department of Health, 1999c, Department of Health, 2001b, Department of Health, 2001c). Government policy on consulting with and involving carers up to 2001 was summarised in a report on mental health carers in Norfolk (Research Plus+, 2001).

The NHS and Social Care Act, 2001 states that every NHS body, including drug treatment services, now has a statutory duty to consult patients and the public in its activities.

A number of 'good practice' guidelines on how to involve carers have been produced nationally (Department of Health, 1999a, Banks and Cheeseman, 1999, Firth and Kerfoot, 1997). These include training for both carers and professionals and payment to carers.

3.2.4 National quality standards for local work with carers.

Based on the Carers Strategy (Department of Health 1999a), the government has established national quality standards for local work with carers and the King's Fund has published a guide to these (Blunden, 2002). This practical, step-by-step guide helps local carer groups and self-help networks carry out a quick self-check of how far they are meeting the Government's standards in ensuring carers can access information, have regular breaks, receive emotional support and health care, and be heard.

More recently some of the national substance misuse carers agencies have published some good practice guidance and quality standards for work with substance misuse carers (Rattenbury and Linnett 2005) see 3.3.6.

3.3 Government policy, research and reports on carers of substance misusers

A wide range of strategies, policies and research reports relating to the needs of and services for carers of substance misusers have been published in the last five years. A selection of them are discussed below.

3.3.1 'Updated National Drug Strategy 2002'

The 'Update of the National Drug Strategy 2002' (Home Office Drugs Strategy Directorate, 2002) focused on preventing young people from becoming problematic

drug users, reducing the supply of illegal drugs, reducing drug related crime and its impact on communities, treatment of substance misusers and harm reduction.

The strategy made frequent mention of parents, carers and families of substance misusers. However, the focus of this was on families where there was a young person who was a drug user or preventing young people from becoming drug users. There was little mention of young carers or adult carers of adult substance misusers.

The strategy recognised that:
'Drug misusers blight not only their own lives, but also those of their families and others close to them. The impact of drug misuse on the parents, siblings, partners and children of drug misusers can include violence, neglect, mental illness, as well as all the side-effects arising from the poverty associated with drug misuse.' (page 18, Home Office Drugs Strategy Directorate, 2002)

The updated strategy increased the resources available by 44% between 2002 and 2005. New areas of spend included more support for parents, carers and families so they could easily access advice, help, counselling and mutual support. The focus for these resources was the most deprived areas of England and Wales, currently suffering the worst drug-related crime.

The strategy stated that, by March 2006, the government would discourage young people from using drugs in the first place and support parents and family members who are worried about drugs through a range of initiatives including:
'Improving services for parents and carers by setting clear standards for the support offered to parents who are concerned about substance misuse or whose family members have a drug problem.' (page 7, Home Office Drugs Strategy Directorate, 2002)

The support to parents and family members was stated in more detail as follows:
'Family members are usually the first to spot that a young person is having problems and the first to provide support, and can influence the success of any drug intervention their child receives. Parents are also a key group needing support in their own right, often experiencing enormous fear and concern and feeling they are dealing with problems alone. This situation cannot continue and the Government is committed to extending provision for parents and families. The Government will be setting standards for local support for parenting across a wide range of issues, including substance misuse, within a proposed National Framework for Parenting Support. Parents caring for a young person with a substance misuse problem will have access to a range of services including information, first aid training and advice on treatment options. Delivering this range of services needs close co-ordination between mainstream and specialist services. Targets have been set for DATs (Drug Action Teams) to ensure that support for families is addressed through the development of substance misuse services for young people. Parents will also be consulted on the development and provision of young people's substance misuse services and service quality standards. Mainstream services are also being encouraged to provide information and support for parents concerned with substance misuse. Young people, too, will be encouraged to involve their parents within programmes of treatment where possible and/or appropriate.' (page 23, Home Office Drugs Strategy Directorate, 2002)

3.3.2 National Treatment Agency for Substance Misuse and 'Models of Care for treatment of adult drug misusers'

The development of drug misuse carer involvement is an integral part of the work of the National Treatment Agency for Substance Misuse (NTA) and it has also made links with mental health carers' initiatives.

As set out in their business plan for 2005/6 (NTA, 2005), the NTA is developing both user and carer involvement in the development of local treatment systems. It is also working to ensure that users and carers are fully involved in the NTA's decision-making processes and that this is reflected at local partnership area and provider level.

The NTA has linked up with NIMHE (National Institute for Mental Health in England) to develop an 'Opening Doors Experts by Experience' user and carer initiative. This group has been involved in delivering training events for commissioners and providers across all regions and has been involved in the specialist substance misuse training for GPs (NTA annual report, 2004a).

The NTA document 'Models of Care for treatment of adult drug misusers' (NTA, 2002) recognised the crucial role of substance misuse carers in the development of substance misuse services. The document stated that 'greater user and carer involvement in planning and developing services will lead to more effective and acceptable services.' and that substance misuse carers 'should be involved in the development of integrated care pathways to develop a more effective drug treatment system'.

The document also states that, in relation to the person that they care for, substance misuse carers can request a review and evaluation of the substance misuser's care plan.

3.3.3 National Alcohol Harm Reduction Strategy for England' and 'Models of Care for Alcohol Misusers'

A national alcohol harm reduction strategy for England was published last year (Prime Minister's Strategy Unit, 2004). The strategy recognised that alcohol can be harmful to the drinker, their friends and family and to wider society. It calculated that:
'The cost of the human and emotional impact suffered by victims of alcohol-related crime to be £4.7bn per annum. Between 780,000 and 1.3m children are affected by parental alcohol problems. Marriages where there are alcohol problems are twice as likely to end in divorce.'

Associated 'Models of Care for Alcohol Misusers' are currently under development. The report of a consultation on the draft document organised by Alcohol Concern (Mike Ward, 2005) emphasised the need to expand the section on 'significant others':
'There was a welcome for the section on significant others but it was overwhelmingly felt that more was required in this area. Indeed more comments were gathered from participants on this than on any other part of the consultation.

The actual section concentrates mostly on child protection and does not say what the role of alcohol services should be with regard to significant others. There is a tradition in alcohol services, particularly the voluntary sector, of working with family members and this is seen as a way of helping to bring the drinker to point of a change. This should be reflected more fully in the document and guidance given on how this role should be undertaken. Most service users consulted wanted their significant others

involved in some way with their treatment and felt that MoCAM ['Models of Care for Alcohol Misusers'] did recognise that friends and family needed support but did not offer any options, or give examples. They discussed the possibilities of counselling services and early interventions for their children.

It was also generally noted that:
• despite its concentration on child protection this section does not mention foetal alcohol syndrome.
• Al-Anon was not mentioned, which appeared to be a missed opportunity to flag up what was perceived as a valuable organisation.'

3.3.4 'Hidden Harm. Responding to the needs of children of problem drug users.'

The inquiry into the impact of parental problem drug users on children (Advisory Council on the Misuse of Drugs, 2003) estimated that the number of children of problem drug users was between 250,000 and 350,000. This was estimated to be between 2% and 3% of children aged under 16 years.

Some specific findings of the Inquiry were:

- The children of drug users described feelings of hurt, rejection, shame, sadness and anger over their parents' drug problems.
- Although the management of problem drug users by general practitioners remained contentious, there were numerous examples of primary care teams providing a high standard of care for problem drug users. A focus on their children appeared much less common.
- Because they were often the main agency in contact with problem drug using parents, all drug agencies should contribute to assessing and meeting the needs of their clients' children. This should be seen as an integral part of reducing drug related harm.
- There were many non statutory organisations working to support children in need. Few were currently providing services specifically aimed at helping the children of problem drug users. There was considerable scope for developing a major contribution in the future, ideally in partnership with the statutory agencies.
- Many problem drug users had frequent contact with the police and the children of problem drug users could be given up to 72 hours 'police protection' if they were at immediate risk.

The inquiry made 48 recommendations covering a wide range of services including drugs and alcohol agencies, primary and secondary health services, mental health services, social services, education, the criminal justice system and voluntary organisations. They concluded that by working together, services can take many practical steps to protect and improve the health and well being of affected children.

3.3.5 'Information Resources for 'Family' Members who are Supporting Drug Users'

Research Works Limited in their report 'Information Resources for 'Family' Members who are Supporting Drug Users' (Research Works Limited, 2003) noted that parents were hungry for information on drugs and drug use. Many of them did not know where to go for this information. Their usual support networks were limited. The report noted that grandparents were in a similar position. They looked for information on the internet and in the library. They could be looking for information in relation to their child as a user and how best to support their grandchild, or they could be

looking in relation to helping their grandchild who was using drugs. In most cases they were unaware of what to look for and how to find it.

The first places substance misuse carers contacted were the GP or a drugs helpline. The research participants reported that a national drugs helpline was inadequate, given the emotional state that they were in. They did not have confidence in the helplines' approach to the problem. The police were another source of advice and information. Some carers had also become involved with the police when they had gone to buy drugs for the person that they cared for. They had not realised what a serious position they had placed themselves in. Some carers cared for substance misusers who were sent to prison. Again this was a new situation for most carers, which they did not feel equipped to deal with at first.

When the research looked at how long partners stayed with a drug user they found that it depended on the length of the relationship. The shorter the length of the relationship, the quicker the partner would leave.

This report also found that rural carers, as well as those who had newly arrived from other countries, were not keen for the wider community to know about their situation.

3.3.6 Carer involvement in substance misusers' treatment

In 2004, as part of the work done for the Audit Commission's management report on drug misuse (Audit Commission, 2004), the European Association for the Treatment of Addiction undertook a study of substance misusers' views of drug treatment (European Association for the Treatment of Addiction, 2004). The study found that carer involvement benefited the recovery of the substance misuser:

'Some users reported that recovery was faster once family members (including children and parents) had received help for themselves and consequently learned how to be more supportive with the user. Advertising services that could help families as a whole was noted as being poor or non existent. It should be noted that individuals also discussed family in terms of other significant relationships that they referred to as though they were family members.'

3.3.7 'Being heard: Notable examples of user and carer organisations'

In 2004, again as part of the work done for the Audit Commission's management report on drug misuse (Audit Commission, 2004), a number of notable examples of user and carer organisations were identified (NTA, 2004b). The carer organisations identified are included in the local projects listed in sub-section 3.6 below.

3.3.8 'We Count Too'

During the research period 'We Count Too' was published (Rattenbury and Linnett, 2005). This provided good practice guidance and quality standards for work with family members affected by someone else's drug use. The report provided an excellent overview of issues related to work with carers of substance misusers and examples of national and local resources.

The report found that some DATs were starting to make links with lead officers for carers within local authorities, and had been able to access Carers Special or Support Grant funding to support family members. They thought that the practice could be used more widely by DATs – both generally and in cases involving dual diagnosis needs.

The report recognised that families and carers of substance misusers came from a diverse range of communities and cultural backgrounds. As some areas of service delivery might, as yet, be underdeveloped in terms of addressing these diverse needs, they suggested that further work was needed to identify the particular needs of different communities and to explore creative ways of meeting them. The 'diverse range of communities' included:

- Black and minority ethnic communities
- Travellers
- Rural communities
- People with disabilities
- Lesbian, gay, bisexual and transgender communities.

The difficulty of encouraging male family members to seek and gain support was also noted. The report suggested some methods that could be used to increase the number of male carers seeking and receiving support.

The report identified local examples of good practice. The Matthew Project in Norwich was highlighted for their family resource room where a wide range of information was available.

3.3.9 Reports on Substance Misuse prepared for the Scottish Executive

In Scotland a considerable number of reports have been produced by the Effective Interventions Unit for the Scottish Executive. They have provided policy and practice guidelines for working with children and families affected by drug use and reviewed services supporting families and carers of drug users.

The document 'Getting our Priorities Right' prepared by the Scottish Executive, (Scottish Executive, 2001) stated that in the field of drug treatment care and rehabilitation, children of drug using parents have often been invisible. Professionals felt ill equipped to manage the often complex needs of both parents and their children and had focused on the adults. Similarly, staff in children's services had lacked the knowledge, skills and confidence to address parent's drug related problems, even when these were clearly impacting on the child with whom they were working. The report stated that it was not enough to protect children from the serious risk associated with parental problem drug use. It was equally important to provide for the wider needs of the child and family, for therapy and support, including help for parents to develop their parenting skills, alongside reducing or stopping their drug use. To do this, they recommended the re-orientation and better co-ordination of adult drug services and childcare services, geared towards early intervention before problems reached crisis point. Staff needed to recognise that their efforts were part of a complex set of interactions, which would change the family as a whole, that not all problems could be solved and that one worker could not solve them alone.

The research found that too often contact with children of problem drug users was in response to a crisis. However, services for children could make a significant difference to their quality of life and subsequent development and adjustment. For example, attendance at a nursery could mean that the child's health and welfare was closely monitored, provided important stimulation and contact with other children and experiences in addition to those from a chaotic household.

The Effective Interventions Unit undertook a review of the impact of drug use on families and carers in order to strengthen the services available to families and carers in Scotland (Effective Interventions Unit, 2002 and Effective Interventions Unit,

undated). They found that many family members received their information on drugs and related problems through the media and from the community. The accuracy of the information could be questionable and the family was not fully informed about drugs, their effects and the nature and course of dependency.

For some the stigma could be extreme, particularly if they were also coping with HIV/ AIDS or hepatitis C. This was due to a lack of a cure, its ability to be transmitted to others and a lack of understanding in society. The perception that HIV /AIDS was a disease largely affecting homosexuals could also cause difficulties and embarrassment for families, especially where there was a homophobic culture within the family or community.

The Effective Interventions Unit found that families in rural areas were left to cope alone as best as they could due to a lack of resources. Challenges identified included families feeling vulnerable, as it was hard to remain anonymous in small communities, stigma and the distance to travel to access services.

The Effective Interventions Unit noted that with black and minority ethnic groups, language difficulties were more likely to arise when a parent or a grandparent sought support. There might also be cultural issues where a young male worker might not be the appropriate person to work with an older Muslim woman. There could also be different cultural use of different drugs in different communities.

As seen in other reports, it was often the female members of the family who sought support rather than the male members. The needs of the male members of the family could remain hidden and unidentified. They often said that they provided 'support to the female carer'.

Families who had to cope with bereavement might require support for a considerable time. There might be feelings of guilt and responsibility. Parents do not expect to outlive their offspring. Bereavement sometimes occurred after recovery, partly due to the physical damage the drug user had suffered previously.

They found that 'Family Support' covered a range of interventions aimed at assisting family members who were affected by a relative's drug use. What families sought support for, and where they sought it, could vary greatly. Very often family members sought support for their substance misusing relative rather than for themselves, and expected treatment for their substance misusing relative to help reduce their own stress. It was suggested that, to be effective in helping families, services should have clear aims and objectives specific to that client group. Since family members and carers reacted and coped differently, it was essential that there was a range of appropriate support available to them. Families needed to possess the knowledge of what support existed and how they could access the support.

3.4 Other reports and research

3.4.1 Dual diagnosis

Policies in relation to dual diagnosis (in this context, people with both substance misuse and mental health problems), have been developing in the past four years.

Enhancing Drug Services (DrugScope and the National Treatment Agency for Substance Misuse, 2003) suggested that 'drug users with mental health issues are so common that dual diagnosis should be expected rather than regarded as exceptional. The application of best practice should not be restricted to small groups

but should be extended to the development of the entire care system.' The handbook recognised that there are a range of mental health conditions and suggested that: 'Where psychiatric disorders and drug use co-exist, both should be considered as primary, with mental health services taking the lead responsibility.'

The Department of Health has issued guidance on treatment for dual diagnosis: 'Dual Diagnosis Good Practice Guide' (Department of Health, 2002b) and also personality disorder (Department of Health, 2003).

There is a continuing debate about the causal relationship between mental health and substance misuse, especially whether cannabis triggers mental health problems or whether cannabis is used as self medication for pre-existing mental health problems. See for example the briefing by Rethink (Rethink, 2005).

3.4.2 Research on young carers

The Joseph Rowntree Foundation commissioned a literature review of children's experiences of domestic violence, parental substance misuse and parental health problems (Gorin, 2004). A summary is available on Joseph Rowntree Foundation website: www.jrf.org.uk/knowledge/findings/social policy/514.asp.

The Joseph Rowntree Foundation also commissioned a qualitative study of 38 young people in Scotland whose parents have or had a drug or alcohol problem (Bancroft et al, 2004).

The Young Carers Research Group, based at the Loughborough University Centre for Child and Family Research, has undertaken considerable research into young carers. The needs of young carers of substance misusers have not been specifically looked at. However the needs of young carers of people with mental health problems have been explored, see for example Aldridge (2002) and Aldridge and Becker (2003). Further information is available on the Young Carers Research Group website: www.lboro.ac.ak/departments/ss/centers/YCRG/.

A few reports have looked at issues relating to black and minority ethnic young carers (see for example the King's Fund Centre, 1992 and the Greater Manchester Black Young Carers Working Group, 1996).

3.4.3 Research on substance misuse amongst black and minority ethnic communities and travellers

Most studies of substance misuse amongst black and minority ethnic communities and traveller communities have focussed on the substance misusers rather than the carers. However, some of these provide some information relevant to carers.

A review of the literature on drug use and related service provision for black and minority ethnic communities highlighted the low level of drug awareness amongst older members of black and minority ethnic communities (Fountain et al, 2003). It also indicated that black and minority ethnic communities have very little experience of drug education and prevention resources that are specifically targeted at their needs.

As a follow up to the above study, the Drug Education Prevention and Information Service held two consultation events on substance misuse with representatives of black and minority ethnic communities (Drug Education Prevention and Information Service, 2004). This highlighted the need to work more closely with black and

minority ethnic communities on drug education and prevention and, where needed, to provide information in people's mother tongue or by word of mouth.

Some research on public health and travellers has been undertaken by Sheffield University in five areas of the country, including Norfolk. It identified considerable lack of knowledge of how to deal with, and fear of, both drug and alcohol misuse amongst travellers living on authorised and unauthorised sites (Van Cleemput et al, 2004).

Substance misuse amongst travellers was discussed in a focus group as part of some research undertaken by Research Plus+ in Norfolk in 2004 (Research Plus+, not yet published). There appeared to be growing concern about drug misuse amongst travellers in the region.

3.4.4 Research on sex workers and substance misuse in Norfolk

There has been considerable research that shows a high incidence of substance misuse amongst sex workers. In Norfolk, the Matrix Project and the Magdalene Group, which both work with sex workers in Norwich, reported that nearly all of the sex workers that they work with use drugs and a large proportion have mental health problems (Research Plus+, 2005 and Research Plus+, not yet published).

3.4.5 Research on offenders and substance misuse in Norfolk

Some research undertaken by Research Plus+ in 2004, on the accommodation and related support needs of offenders in Norfolk (Research Plus+, 2005), identified that a high proportion of offenders had substance misuse problems. Amongst offenders supervised by the Norfolk Probation Area, 54% had drug misuse problems related to their offending and 49% had alcohol misuse problems related to their offending. Amongst young offenders supervised by the Norfolk Youth Offending Team, 29% had substance misuse problems associated with their offending. A significant proportion of offenders also had mental health problems.

3.5 National organisations

As part of the research some national organisations were contacted to determine what provision is available nationally for carers of substance misusers. Information was also obtained from other sources. These included, in alphabetical order:

3.5.1 Adfam

Adfam is a national voluntary organisation working with families affected by drugs and alcohol and is a leading agency in substance related family work. It provides a range of publications and resources for groups, services and families themselves about substances and criminal justice. They are investigating the support given to carers and carers' assessments. Adfam reported that there are only one or two local authorities who are providing any sort of carers assessments at the moment and some groups shy away from being in touch with local authorities. More information is available on their website: www.adfam.org.uk

3.5.2 Al-Anon

Al-Anon offers understanding and support for families and friends of problem drinkers, whether the alcoholic is still drinking or not. The parents, children, wives, husbands, friends and colleagues of alcoholics could all be helped by Al-Anon and Al-Ateen whether or not the drinker in their lives recognises that a problem exists.

At Al-Anon group meetings members receive comfort and understanding and learn to cope with their problems through the exchange of experience, strength and hope.

The sharing of problems binds individuals and groups together in a bond that is protected by a policy of anonymity. Members learn that there are things they can do to help themselves and indirectly to help the problem drinker. Changed attitudes, which come from greater understanding of the illness, may result in the drinker seeking help. Al-Ateen, part of Al-Anon, is for young people aged 12-20 years who have been affected by someone else's drinking, usually that of a parent. More information is available on their website: www.al-anonuk.org.uk

3.5.3 Alcohol Concern

Alcohol Concern do not work directly with carers but are currently running a Parenting and Alcohol Project. It is looking at how to deliver parenting support to alcohol users and the provision of information on alcohol misuse to parenting professionals. Alcohol Concern has previously produced toolkits on working with the children and families of problem drinkers. More information is available on their website: www.alcoholconcern.org.uk

3.5.4 Carers UK

Carers UK (formerly the Carers National Association) is a leading campaigning, policy and information organisation for carers. They are a membership organisation, led and set up by carers in 1965 to have a voice and to win recognition and support for carers. Their campaigns are rooted in the experiences of carers, and aim to improve carers' lives. Carers UK is a leading provider of information to carers with a free advice service. Carers UK is in touch with over half a million carers through its membership and networks of branches and affiliates. The extent to which it works with substance misuse carers is not known. More information is available on their website: www.carersuk.org

3.5.5 The Drugs Education and Prevention Information Service

The Drugs Education and Prevention Information Service (DEPIS) has been available on the Department of Health Website since July 2002. It is managed by DrugScope. The aim of DEPIS is to inform drug education practitioners and contribute to the evidence based around drug education and prevention for young people and their parents and carers. Central to the DEPIS project is the dissemination of examples of good practice. More information is available on their website: http://199.228.212.132/doh/depisusers.nsf/Main?readForm

3.5.6 FAMFED (Federation of Family Support Groups)

FAMFED is a recently established national membership organisation for groups and projects working with family members affected by substance misuse. It aims to provide support, information and training for member organisations on a range of relevant issues.

3.5.7 Families Anonymous

This is a worldwide fellowship of relatives and friends of people involved in the abuse of mind-altering substances, or with related behavioural problems. A number of local groups operate across the UK. More information is available on their website: www.famanon.org.uk

3.5.8 Families Plus, Clouds

Part of the charitable organisation Clouds, the work of Families Plus is devoted to family members and others who want help in understanding and coming to terms with the effects of living with the substance misuse of others. More information is available on their website: www.clouds.org.uk

3.5.9 FRANK
Frank, the official government 24 hour helpline and website, offers confidential drugs information and advice. More information is available on their website: www.talktofrank.com

3.5.10 Lifeline
Lifeline is a non profit-making organisation and a registered charity that helps people who use drugs and the families of people who use drugs.
More information is available on their website: www.lifeline.org.uk

3.5.11 National Association for the Children of Alcoholics
The National Association for Children of Alcoholics was set up in 1990 to address the issues related to children growing up in families where one or both parents suffer from alcoholism, or similar addictive problems. This concern includes children of all ages, many of whose problems only become apparent in adulthood.

They have four broad aims:
- To offer information, advice and support to children of alcoholics – through its free confidential helpline and website.
- To reach professionals who deal with children of alcoholics in their everyday work, educating them as to their specific needs.
- To raise the profile of children of alcoholics in the public consciousness.
- To promote research into the nature and extent of the problems they face.

More information is available on their website: www.nacoa.org.uk

3.5.12 PADA (Parents Against Drug Abuse)
PADA is a national voluntary organisation working with families affected by substance misuse. PADA provides information, teaches coping strategies and where necessary signposts people to other agencies. PADA provides both local and national services. The local services include one to one sessions, group sessions and outreach work. They also provide training both locally and nationally, a national telephone helpline for family members affected by substance misuse and a website with a database of local support groups and drug treatment services. PADA reported that groups are not as popular as they once were because of privacy and shame issues. People prefer to talk to a helpline. More information is available on their website: www.pada.org.uk

3.5.13 Princess Royal Trust for Carers
The Princess Royal Trust for Carers is one the largest providers of comprehensive carers' support services in the UK. Through its network of 118 independently managed Carers' Centres, young carers services and interactive website, the Trust provides information, advice and support services to 180,000 carers including 10,300 young carers. The Norwich and District Carers Forum is affiliated to the Trust.

The Trust, set up in 1991, provides training and support for Carers Centres, as well as raising funds for development work. It has a range of grant schemes for carers, including an Educational Bursary Scheme, a Carers' Relief Fund for carers in particular financial difficulties and a Young Carers Fund. The extent to which it works with substance misuse carers is not known. In 2002, they jointly published a report with the Children's Society, on professionals failing to recognise the needs of significant numbers of young carers. This included young substance misuse carers. More information is available on their website: www.carers.org

3.5.14 The Adult Children of Alcoholics and Dysfunctional Families

The Adult Children of Alcoholics and Dysfunctional Families are a fellowship of men and women who were raised in an alcoholic, addicted or dysfunctional home. Adult Children of Alcoholics and Dysfunctional Families follow a 12-Step 12-Tradition programme. More information is available on their website: www.acauk.org

3.5.15 National helplines

There are a number of national helplines for substance misusers and carers of substance misusers.

Help lines specifically for substance misuse carers include:

- Al Anon
- Al-Ateen
- Families Anonymous
- National Association for the Children of Alcoholics
- PADA – Parents Against Drug Abuse

Helplines that can provide general advice on drug and alcohol misuse include:

- Alcohol Concern
- Alcoholics Anonymous
- Drinkline
- Frank - national drug help line
- Narcotics Anonymous
- Release
- Re-Solv
- The Alliance: Advocacy for Drug Treatment

3.5.16 Useful websites

A list of national and local websites, related to substance misuse is available on the NORCAS website: www.norcas.org.uk/websites.html

3.6 Organisations in other parts of the UK

As part of the research, information was obtained on agencies that provide support to carers in other parts of the UK. It includes agencies identified as 'notable examples' of carer organisations (NTA, 2004b).

3.6.1 Carers Against Substance Abuse

Carers Against Substance Abuse (CASA) was formed in 2003 to provide advice and support to the families and partners of users in Gateshead. More information is available on the website: www.nta.nhs.uk/programme/national/being_heard.pdf

3.6.2 Family and Friends

Runs a helpline and other services based in Leamington Spa. Telephone: 01926 314837.

3.6.3 Family Drug Support

Family support based in Hertfordshire. Telephone: 01981 251155.

3.6.4 Focus Counselling Services

Focus Counselling Services, based in Bury St Edmunds in Suffolk, offer a free assessment and intervention service to the client, close relative or partner. These include weekly groups or individual counselling to allow family members to discuss the problems caused by alcohol and substance misuse. More information is available on their website: www.focus12.co.uk/

3.6.5 Lauren's Link

Lauren's Link is a Derby based helpline and website for any family member who has been bereaved through drug use. More information is available on their website: www.laurenslink.org.uk

3.6.6 Hettys
Hettys is a support network for parents, carers, family and friends of illicit drug users. They work with parents, carers, family members or friends of drug users who need access to confidential advice, support and information in the Nottinghamshire area. More information is available on their website:http://www.hettys.co.uk/

3.6.7 GASPED
Family Support Services based in west Yorkshire. Telephone: 01924 787501.

3.6.8 Newcastle PROPS
Newcastle PROPS - Positive Response to Overcoming Problems of Substance misuse in the family - is a community based project set up to help people with a substance misuser in the family. It covers all of Newcastle. More information is available on the government website (in the communications section of the Works Pages): www.drugs.gov.uk

3.6.9 Oasis
Oasis is a project based in Lincolnshire to support families who have a family member using drugs or alcohol.

3.6.10 PANIC
PANIC (Parents and Addicts Against Narcotics in the Community) is an independent user group funded by Stockton DAT. Activities include complementary therapies, support groups for families and a user group. More information is available on the website: www.stockton.gov.uk/citizenservices/33404/82711/87921/

3.6.11 Sheffield Family and Friends Alliance
The Sheffield Family and Friends Alliance brings together representatives from Sheffield family support groups and agencies. They meet regularly to share information and look at ways to work together to meet the recognised needs of families. More information is available on the website: www.sdat.org.uk/fandf2.htm

3.6.12 SPODA (Supporting Parents of Drug Abusers), Derbyshire
SPODA provides a family support helpline, support groups, one to one outreach and advocacy services. They are willing to share policies and procedures with others developing similar services. More information is available on the website: www.highpeakscvs.org/communitywebspace/SPODA.htm

3.6.13 South Yorkshire Parents and Drugs Support (SYPADS)
SYPADS is willing to share information on running a helpline.
Telephone: 0114 276 7954.

3.6.14 Support Group for Parents and Partners of those with a Drug Problem.
This support group is based in Weymouth and is willing to share its constitution and terms of reference with other groups. Telephone: 01305 770995.

3.7 Initiatives for carers in Norfolk
As part of the research, a number of initiatives to support carers in Norfolk were identified. Further information was obtained from the survey of agencies, see Section Four.

3.7.1 Carers' agencies in Norfolk

There is a network of agencies for carers across Norfolk. These groups are for carers in general, not specifically substance misuse carers. The main agencies providing services to adult carers in Norfolk are Norfolk County Council Social Services, Norwich and District Carers Forum, West Norfolk Carers Association, and Crossroads – Caring for Carers. Some GP practices also run carer support groups, particularly in South Norfolk. Other groups are organised by individuals. The Norfolk Carers helpline is available 24 hours a day to people of all ages.

There are some specific support services for mental health carers. These include support provided by the Mind Mental Health Carers Support initiative and Rethink. The Norfolk and Waveney Mental Health Partnership NHS Trust has also set up a Carers' Council to consult with mental health carers.

For young carers there are 25 young carers projects run by a number of agencies (Crossroads – Caring for Carers, NYCS, Norwich and District Carers Forum, CONNECTS & Co and NCH) and co-ordinated by Norfolk County Council Social Services.

The substance misuse services in Norfolk include a range of statutory, voluntary and community based drug and alcohol treatment agencies, one voluntary agency specifically supporting substance misuse carers, a range of self help groups for substance misusers and some self help groups for substance misuse carers.

The extent to which these agencies provide support to substance misuse carers was explored in the survey of agencies, and the findings are presented in Section Four of the report.

3.7.2 Norfolk Carers Partnership and the 'Norfolk Carers Action Plan'

In Norfolk, the Norfolk Carers Partnership (a partnership of Norfolk County Council, Norfolk Health, carers, voluntary agencies and the Department of Work and Pensions) produces the 'Norfolk Carers Action Plan'. The current Action Plan includes a couple of references to substance misuse carers (Norfolk Carers Partnership, 2005).

3.7.3 The Carers Grant and carers assessments

The Norfolk Carers Grant, administered by Norfolk County Council Social Services, provides three types of funding for carers:

- Small grants to carer support groups
- Large grants spent within the department or by agencies to fund a service for users so that carers can have a break, or to fund a service direct for carers
- One-off direct payments for carers eligible for a carer's assessment who are 'at critical risk' of being unable to continue to care.

The national quality standards for local work with carers (Blunden, 2002) are an integral aspect of all applications for the Carers Grant in Norfolk.

In 2004/5, 67 small grants (usually of £250) were allocated to carers' support groups. None of these were specifically catering for substance misuse carers, but twelve of them stated that the carers they covered included 'alcohol' or 'drug' problems or covered 'all groups'. The extent to which they worked with substance misuse carers was not specified.

The amount spent within the department or by agencies for direct or indirect support to substance misuse carers through the large grants was £10,000 in 2000/2001. This increased each year and was just over £20,000 in 2004/5. Agencies given a grant included: Hebron House, NORCAS (advocacy for service users), the Magdalene Group, Linking Together and the Matthew Project (photography with service users). It was also spent on additional residential drug rehabilitation care and additional day care.

In 2002, under the Carers and Disabled Children Act 2000, the Norfolk County Council Social Services decided to allocate £30,000 to pilot one-off direct payments to adult carers looking after someone aged 18 and over and who was eligible for social services. Carers would be eligible for a direct payment if they were 'at critical risk' of being unable to continue to care after all appropriate community care services had been provided. £700 was allocated for substance misuse carers in both 2002/3 and 2003/4. None of the £700 was spent in 2002/3 and £386 was spent in 2003/4.

Norfolk County Council Social Services has been piloting the use of Carers Grant funding to routinely provide assessments in relation to carers of older people and carers of people with a physical disability. These are undertaken by a member of staff who works in the same team that provides the assessments of the person cared for.

3.7.4 Norfolk Area Child Protection Committee Protocols

The Norfolk Area Child Protection Committee (ACPC) has a protocol on the principles of working together to provide services for children in need where substance misuse is a potential or actual concern (Norfolk Area Child Protection Committee, undated1) and another protocol on services for children in need who have parents with mental health and / or substance misuse problems (Norfolk Area Child Protection Committee, undated 2).

3.7.5 Information for carers in Norfolk

The 'Drugs and Alcohol Services in Norfolk' booklet produced by the Norfolk DAAT (Norfolk DAAT, 2004) includes information on agencies that provide support to substance misuse carers, particularly under the sections on 'Self-help Organisations in Norfolk' and 'National Organisations'. Four of the drug and alcohol treatment services also specifically state that they provide support to family members and other concerned people (Contact NR5, the Matthew Project, NORCAS and T2).

The 'Who Cares?' booklet (Norfolk County Council, et al, 2005) contains useful information for a wide range of carers in Norfolk, including information on carers' assessments, taking a break, health and wellbeing, money matters and learning opportunities. It has only limited information specifically for substance misuse carers – it includes contact numbers for two projects that work with substance misuse carers (the Matthew Project and Linking Together) and the website address of one national and one local project that works with substance misuse carers (the Matthew Project and Adfam).

Local helplines include:

- Norfolk Carers helpline
- The Matthew Project helpline
- Local branches of some national helplines
- Samaritans in Norwich, Great Yarmouth and King's Lynn.

The Norfolk Carers Agency Partnership (which includes representation of the main carer's agencies in Norfolk) publishes a quarterly newsletter 'The Norfolk Carer', which is sent out to carers in Norfolk.

The Heron website provides information on health services in Norfolk and it is available to both professionals and the general public. It does not itself include information on sources of support for substance misuse carers. Instead it links the individual to the Norfolk DAAT website, which includes limited information on sources of support for substance misuse carers.

3.7.6 GP Registers of carers

In line with government policy (Department of Health 1998a), a number of GP surgeries in Norfolk have taken action to set up Carers Registers. However, the research did not find any evidence that these specifically include substance misuse carers.

3.7.7 Consultation and involvement

A register of carers, who are interested in being consulted about or involved in the development services, has been set up, called the 'Norfolk Carers Voice'. The questionnaire for interested carers to complete (Health Information Team and the Norfolk Carers Partnership, 2004) includes reference to a 'drug problem' and an 'alcohol problem'. At the time of the research, only three of the 160 carers registered with the 'Norfolk Carers Voice' were substance misuse carers.

3.7.8 Dual diagnosis

In response to the Department of Health guidance on dual diagnosis and personality disorder (Department of Health, 2002 and Department of Health, 2003), a Norfolk wide definition of dual diagnosis has been developed under the auspices of the Norfolk PCTs (Pike, 2004a and 2004b). The definition encompasses people with a wide range of mental health problems, not just those diagnosed with a severe and enduring mental illness. The definition is:
'An individual who presents with co-existing mental health (and/or Personality Disorder) and substance misuse problems (drugs and/or alcohol).'

This definition was agreed late last year (November, 2004) and the first stage of implementation is concentrating on the training of staff. In the longer term it could lead to a significant increase in the availability of mental health support services for people with substance misuse problems. The Norfolk DAAT supports the implementation of provision for this client group, using an integrated model of service delivery. This means that substance misusers can receive both mental health and substance misuse services at the same time.

The University of East Anglia is currently undertaking a needs assessment of the number of people with dual diagnosis. They are due to report at the end of 2005. They are developing a tool to screen for substance misuse in mental health services and a tool to screen for mental health in substance misuse services and will be identifying 'hotspots'.

3.8 Summary

- Over the last fifteen years, the needs of carers in general have been increasingly recognised. New legislation, strategies and guidance for carers, including substance misuse carers, have been introduced.
- A wide range of reports relating to the needs of and services for substance misuse carers have been published in the last five years.
- As part of the research, some national organisations and helplines were contacted to determine what provision is available nationally for substance misuse carers.
- Information was obtained on local agencies that provide support to substance misuse carers in other parts of the UK. These provide potential models for services in Norfolk.
- Initiatives for carers in Norfolk were also identified.
- All of these highlighted a wide range of issues affecting substance misuse carers.

Section Four
Sources of Support for Carers of Substance Misusers – Findings from the Survey of Agencies

4.1 Introduction

This section presents the findings from the survey of agencies in relation to support to adult carers of substance misusers. In total 31 completed questionnaires, from 28 agencies, were returned. The response rate was 61%. Information from the questionnaires on support to young carers is presented in Section Nine. A list of the organisations that completed the questionnaire is provided in Appendix 1.

4.2 Support services provided for substance misuse carers

The support services provided by different types of agencies were examined separately.

4.2.1 Support services provided to substance misuse carers by statutory drug and alcohol treatment agencies

A total of five completed questionnaires were received from teams in the three statutory drug and alcohol treatment agencies. The services provided by the statutory drug and alcohol treatment agencies concentrate on the substance misusers. Consequently, most of them reported that they do not offer many services to the parents, carers or affected others of drugs and alcohol users. Examples of support provided were:

'Telephone support, support during sessions with clients or occasionally one to one support.'

'On an informal basis – and tends to be educative. Unless I have permission from clients to specifically discuss their case, then the support is very general.'

A team of substance misuse social workers work in conjunction with the local community alcohol and drug services. Those who completed questionnaires reported that they provided some support to the carers of substance misusers, including carrying out carers' assessments. The degree to which they were able to support carers seemed to vary and few carers' assessments appeared to have been undertaken:

'Information, advice, advocacy, emotional support.'

'Carers assessments, occasional accessing of funds for e.g. groceries / holidays, pastoral / listening support.'

'Services for carers are more limited and aside from offering general advice and support there are no specific services that I can offer directly. Sometimes as a result of a carers assessment a carer may be offered a limited service such as a respite break or access to a leisure activity or a specific item that helps with providing care e.g. a washing machine.'

4.2.2 Support services provided to carers by voluntary and community drug and alcohol treatment agencies

Five voluntary or community based drug and alcohol treatment agencies completed questionnaires. Some provide considerable support services to carers of substance misusers, in particular the Matthew Project and NORCAS.

NORCAS provide:

'Counselling and information to carers and any 'affected others'.'

The Matthew Project provides a range of services that are available for carers. These are:

- Counselling and Support Team: This service provides counselling and support sessions on a fairly regular basis to parents and carers through one to one sessions.
- 24 Hour Helpline: This service receives many calls from parents, carers, young people, partners etc on a regular basis who are concerned about substance misuse. Advice, support and referrals are made.
- Retake: This is a 10 week photography/group work course based at Norwich Arts Centre for people with drug and alcohol problems. The funding for this was originally provided to give carers a respite. Although the funding has changed this course is continuing.
- Info Point: This is a resource room where parents/carers can book appointments to use the internet, books etc. to find out about a subject. It is deliberately limited in its stock. Funding for this no longer exists, but it is used in conjunction with advice sessions etc.
- Housing Support: Provision of a floating support service to people in tenancies. As part of this, support is offered to people who may be carers.
- They also provide support to young people who may be carers, see Section Nine.

Contact NR5, a community based substance misuse service funded by the Norwich Primary Care Trust and the NELM Development Trust, provides one to one assessments of carers' support needs and sometimes also offers treatments.

Focus Counselling Services, based in Bury St Edmunds in Suffolk, provide services to substance misusers and their carers. Although not in Norfolk, Focus provides services to people in Norfolk who live close to the Suffolk border. They provide an individual counselling service and weekly support groups for carers:
'It is important for recovery and the rebuilding of relationships with family members that as far as possible they are included in the treatment programme.'

The Diana Princess of Wales Treatment Centre for drug and alcohol rehabilitation in North Norfolk, which is run by ADAPT (Alcohol and Drug Addiction, Prevention and Treatment), provides services to substance misusers from across the UK. They reported that they provided limited counselling sessions for carers along with the misuser.

It was pointed out by another agency that:
'Residential rehabs are increasingly offering family services that enable carers to receive support, these services may be appropriate for some individuals.'

4.2.3 Support services provided to carers by voluntary substance misuse carers support agencies

Two voluntary substance misuse carers support agencies completed questionnaires.

Linking Together, based in West Norfolk provides:
'Face to face, telephone support, outreach drop in sessions, advocacy support, support through court cases, practical support and befriending.'

One of the Families Anonymous local groups reported that the organisation provides:
'Support to families and friends of substance misusers through local support groups. There is also a national help line.'

4.2.4 Support services provided to carers by carers' agencies

Five carers agencies completed questionnaires.

The West Norfolk Carers Project reported that they do provide support to substance misuse carers, however:
'This is minimal. As an agency, we work very closely with the Linking Together project at North Lynn, King's Lynn. Through this work our opportunities to support carers of misusers is growing.'

The Norwich & District Carers Forum reported that they provide:
'Information and signposting, emotional support.'

Norfolk Carers Helpline provide:
'A telephone helpline service providing information and emotional support.'

Thetford Crossroads reported that they:
'Provide practical support to carers in the community. At this present moment in time we do not have anyone on our caseload that we are aware of.'

King's Lynn Crossroads reported that they do not provide a service to substance misuse carers but they did provide some information on the needs of substance misuse carers.

4.2.5 Support services provided to carers by mental health agencies

Five mental health agencies completed questionnaires.
There are three mental health support services teams in Norfolk. They are staffed by social workers and cover North Norfolk, South Norfolk and Broadland.

In North Norfolk, the service provided is:
'Advice and signposting to other agencies that provide support if wanted. Carers assessments can be organised if required.'

In South Norfolk the service provided is:
'Informal support, such as listening to a partner of a client who has a substance misuse problem and who needs to talk through an issue. We do not offer any formal support or do carers assessments.'

In Broadland:
'We primarily help people with mental health problems. Everyone is different. We will work with people if they are a carer of someone that we already work due to his/her mental health problems or if they have mental health problems themselves. If so, we can then assess them for any of the services that we provide – individual support, provision of information on carers' support services, liaison with other agencies including drug and alcohol treatment services, anger management or assertiveness group. We also look at other issues e.g. housing. We look at what the person's needs are.'

The three Mind groups in Norfolk have recently appointed mental health carer workers. Two of them completed questionnaires. They focus on mental health rather than substance misuse:
'Not as a direct result of substance misuse, although sometimes there are issues of such misuse for some carers. Where there are dual diagnosis issues we work with NORCAS.'

4.3 Protocols for work with substance misusers carers

The agencies were asked what 'national or local standards or protocols' they followed in their work with carers. Most of the agencies said that it was not applicable and some said that they did not work to any protocols with carers. In further discussions, it was suggested that these responses could be due to agencies using different terminology to that used in the questionnaire. Sixteen of the 31 agencies provided some information related to standards or protocols.

One of the statutory drug and alcohol treatment agencies mentioned the:
'Norfolk (CA) Carers Needs Assessment/Review and Support Plan'.

Another statutory drug and alcohol treatment agency did not know of any protocols for adult carers, but said in relation to young carers:
'We have clear guidelines in relation to child protection and ACPC protocols (Area Child Protection Committee). We provide trainers for the ACPC Substance Misuse and the Family training module.'

Another statutory drug and alcohol treatment agency said:
'I am not aware of any protocols. Confidentiality is a big issue.'

The substance misuse social workers said that they offered carers assessments to some carers or worked to the Carers Act.

The voluntary / community drug and alcohol treatment agencies most frequently said that they worked to the Norfolk DAAT guidelines. Other standards mentioned were the NTA and DANOS (Drug and Alcohol National Occupational Standards) standards. The Matthew Project has protocols and policies with each of its partner agencies. One agency said that the QUADS (Quality in Alcohol and Drug Services) standards (Alcohol Concern and DrugScope, 2000) applied to all service users. Other agencies said that their staff worked to professional standards or guidelines.

One agency asked: 'Which ones would those be?'

The two voluntary substance misuse carers support agencies said that they either followed the Good Practice Guide and Quality Standards for work with families affected by drug use, which were about to be published (Rattenbury and Linnett, 2005), or the internationally established 12 step pattern.

One carers' organisation referred to confidentiality, data protection and risk assessment procedures.

4.4 Funding for work with substance misusers carers

The agencies were asked how their work with substance misuse carers was funded. One statutory drug and alcohol treatment agency said that the work that they did with carers was not funded:
'It is not funded and not part of our service agreement with the DAAT. It goes with the territory'.

The substance misuse social workers had a small amount of funding for work with carers, which was ring fenced. The voluntary / community drug and alcohol treatment agencies tended not to have specific funding for their work with carers. The Matthew Project commented 'we do not have any funding which is specifically set aside for work with carers. This work has come about as our service developed and it is

becoming a vital part of our work'. They 'beg, scrape and use money which is not ring fenced'.

The carers agencies were able to access the Carers Grant. Some of the mental health agencies were able to access money from social services, whilst others were able to access PCT / mental health trust funding. Again, some of the agencies did not get specific funding for work with substance misuse carers.

One organisation commented that a barrier to providing support to substance misuse carers was that the funding for Linking Together in the west of the county was uncertain.

4.5 Research awareness

The agencies were asked if they knew of any national or local research or reports on the needs of substance misuse carers. Only six agencies were, and one agency said that they 'hope there is'. Those that were aware of any research or reports most frequently mentioned work by Adfam. Other responses were that several counties had completed similar research to this project, work by Alcohol Concern and that the Royal College of Psychiatrists and the British Psychological Society both have ongoing research projects.

4.6 Main issues faced by carers of substance misusers

The agencies were asked what, in their experience, were the main issues faced by carers of substance misusers. They provided a wealth of information on this.

The financial consequences of having a family member with a substance misuse problem was mentioned as a major problem. Sometimes the parents funded their child's drug habit to prevent them from stealing. This could prevent them from seeking help from agencies that help with debt as they would have to admit that they were caring for a substance misuser.

Another issue mentioned was the lack of information. Some carers needed information to counteract the misleading information that sometimes appeared in the media. They also needed specific information with regards to the effects of the addiction and any treatment for the substance misuse.

Some of the agencies said that isolation and guilt were the main issues. These prevented the carer from seeking help.

Some carers were helping the user to buy their drugs. Where they were buying illegal drugs, rather than alcohol, there were legal implications for the carer. Some carers had confronted the dealers in an attempt to prevent the substance misuser from being supplied with the drugs.

One person summed up the main issues as being 'financial, physical, psychological, emotional, medical, spiritual, social, educational and sexual.'

4.7 Effects of substance misuse on carers

The agencies were asked what they saw as the effects on the different types of carers. This could be parents, partners, children or friends.

The agencies said that the carer needed to get support for themselves to protect their own needs. For parents and other family members, they needed to have access to

relevant information about the effects of the drug or alcohol, the effects of addiction and the law.

The effect on some carers was isolation and shame. Some did not understand why the person was a substance misuser. They might blame themselves for the substance misuse problem.

One agency had found that there could be several different GP responses to alcohol addiction ranging from very little support, to prescribing pills for a home detox or admission to hospital for a detox.

A number of agencies identified issues related to dual diagnosis of mental health and substance misuse. One agency said that carers might find themselves trying to work with two sets of agencies. A number of agencies said that this could cause frustration for the carer. It was suggested that:
'Mental health services separate drug and alcohol out from mental health issues, making 'dual diagnosis' something that is left with little or no resources available.'

One agency said that locally the mental health services left someone with a dual diagnosis to the substance misuse teams and waited for that issue to be resolved before re-engaging with the person. However, another agency said:
'If there is a dual diagnosis the more acceptable diagnosis is discussed and used to mask/hide the misuse problems.'

4.8 Service entitlement and barriers to obtaining services
When asked what support and services a substance misuse carer was entitled to, nine of the responses mentioned a Carers Assessment. Another agency said that they were entitled to an assessment of need.

When the agencies were asked about the barriers to providing services for substance misuse carers they again provided a wealth of information. One of the agencies said that the substance misuse carers were not aware of what they were entitled to. Other barriers mentioned were stigma, isolation and shame. This made it harder for agencies to identify people who were substance misuse carers. Due to the legislation, there was also a perception that services for carers were aimed at the user so the carer could then get a break. It was pointed out that not all of the family members are on good terms with the substance misuser.

Some substance misuse carers might wish to receive services on a one to one basis and not as part of a group. As already commented in Section 3, a lack of information was raised as a barrier to providing services to substance misuse carers.

Several people said that there was a lack of resources in general and especially for respite care. It was pointed out that there were a limited number of support agencies for substance misusers and there were even fewer for carers.

One agency raised the concern of many carers, that of confidentiality issues. The agency said that sometimes they would like to work with both the service user and their family but the service user did not wish them to be in contact with the family.

One agency said of substance misuse carers:
'They hate the substance misuse but may still like or love the person. Where do they get support with that?

4.9 Gaps in support

The agencies were asked if they were aware of any gaps in the support that was provided to substance misuse carers. Four of the agencies said that they were not aware of any, with a further two not replying to the question. Other agencies said that they were either 'not sure' or did not know because of their limited contact with substance misuse carers .

The eighteen agencies that did perceive a gap in provision noted that substance misuse carers needed information about their entitlement to services.

Some of the agencies saw the need for support services that were dedicated to substance misuse carers and young substance misuse carers. One agency said that what support was available was not ring fenced for carers. Another agency pointed out that the carer needed to be taken into account when there is an assessment taken of the user.

Some agencies said that there were few services for carers due to a lack of funding. This also impacted on the amount of respite care that was available. Another funding issue raised was the time and expense of getting people to meetings across a large county.

One agency pointed out that there was little family or community support when a person was identified as having a substance misuse problem. It was also pointed out that there was no culturally specific support.

One of the agencies said that there was a need for more therapy. This could be family therapy, individual therapy or therapy aimed at children.

4.10 Suggestions to improve services

The agencies were asked for their suggestions on how to improve the support provided to substance misuse carers. Four agencies did not have any suggestions and a further two agencies did not respond to this question.

One suggestion was to increase the publicity and awareness aimed at carers, their needs and how they access support and information.

Another suggestion was more funding. This could be for respite care. Another suggestion was to increase the number of trained counsellors / therapists available. Another suggested improvement was the funding of more carers groups around the county. One voluntary support agency thought that there should be more money put into funding their national telephone helpline and national office hours.

One suggestion was for more systemic work and working with the community, the schools and the family.

Another suggestion was to use this research to break down the barrier so that it was recognised that someone caring for someone with a substance misuse problem is not seen as a 'lesser' carer than other carers, and that it as hard work as caring for someone with a more 'recognised' illness or disability.

The Matthew Project also reported that working with carers had sometimes also enabled them to engage with the substance misusers themselves.

4.11 Awareness of other agencies

The agencies were asked what other agencies they were aware of. Six of the agencies that responded were not aware of any other agencies. A further fourteen only mentioned one or two agencies. One agency, however, was able to mention 24. The local agencies that were most well known were Linking Together in West Norfolk, the Matthew Project and NORCAS. The national agencies that were mentioned most frequently were PADA, Adfam and self help groups such as Al Anon.

Unfortunately some of the information was not correct – a couple of the agencies mentioned were no longer in existence.

4.12 Mapping of services for substance misuse carers

Chart 4.1 summarises the main support available to carers of substance misusers in Norfolk. This is based on the responses to the agency questionnaires, telephone calls to agencies that did not respond and other information obtained during the course of the research.

This shows that the main sources of sustained support are the Linking Together Project in West Norfolk, NORCAS, the Matthew Project, and the self help support groups. There are seven Al-Anon families groups across the county for carers of people with alcohol problems but only two Families Anonymous groups for carers of people with drug problems. In cases of dual diagnosis, some of the support services for mental health carers also provide support to substance misuse carers. However the emphasis is usually on the mental health issues.

The research revealed that carers also approach other agencies for help and support related to the care of the substance misuser, see Section Seven. Carers also have access to national organisations and helplines, as listed in Section Three.

One substance misuse treatment agency concluded:
'I do not see that parents are currently offered very much at all. To a large extent, they are not included in the treatment plans of service users and do not appear to have been considered as important to involve in any structured way. There is very little in the way of responsive services to which they can refer themselves. Information is available, though a more tangible support (and I do not just refer to emotional support) is certainly more vague. I think that families need to be treated together as well as individuals for a service to be realistic.'

Chart 4.1 Agencies providing support to carers of substance misusers in Norfolk – based on the survey of agencies

Name of agency	Support provided
Substance misusers self help groups	
Al-Anon Family Groups	Provide support for families and friends of problem drinkers. They run seven groups in Norfolk – Norwich (two groups), Sheringham, Donwnham Market, Fakenham, Gorleston and Thetford. They also run groups in Wisbech in Cambridgeshire and Lowestoft in Suffolk, which may be nearer for some Norfolk residents.
Al-Ateen Groups	Provide the same service as Al-Anon Family Groups but for young people aged 12 to 20 years. There are no Al-Ateen groups in Norfolk but young people aged 16 years and over can attend the Al-Anon family groups.
Families Anonymous	Provide support groups for families and friends of those with a drug problem or related behavioural problems. There are three groups in Norfolk: two in Norwich and one in Gorleston.
Overcomers Dependency Support	A Christian support system which provides confidential help for individuals and families who wrestle with alcoholism and other addictions and compulsions. They run one support group in Norwich. It is run by one of the groups that run one of the Families Anonymous groups in Norwich.
Voluntary and community based agencies	
Linking Together	One worker in West Norfolk. She works primarily with substance misuse carers but also provides limited support to substance misusers to assist the carers.
The Matthew Project	24 hour help line, counselling and support, a resource room and limited respite for carers.
NORCAS	A range of services available to substance misusers in Norwich, North Norfolk and Great Yarmouth. The Norwich based counselling service is available to carers.
Contact NR5	Available to people in the NR5 area of Norwich. Undertake some one to one assessments of carers, treatments sometimes offered.
Norwich Community Support Workers	Work with families in the NELM area of Norwich. This includes support to substance misuse carers.
Focus Counselling Services	Based in Bury St Edmunds, Suffolk, they provide services to Norfolk substance misusers and their carers who live close to the Suffolk border. Individual counselling and weekly support groups provided for carers.
Diana Princess of Wales Treatment Centre	Provides a nationwide drug and alcohol rehabilitation in North Norfolk. They provide limited counselling sessions for carers along with the misuser.

Chart 4.1 Agencies providing support to carers of substance misusers in Norfolk – based on the survey of agencies (continued)

Name of agency	Support provided
Voluntary and community based agencies (continued)	
Carers agencies, including Norwich and District Carers Forum, West Norfolk Carers Association and Crossroads – Caring for Carers local schemes	There is a network of general carer agencies and local Crossroads groups across Norfolk. They have little contact with substance misuse carers.
Crossroads Carers Helpline	This is available to substance misuse carers, but the staff do not have any specialist training in substance misuse.
Rethink	Run a support group and events for mental health carers. Provide some support to carers of substance misusers where the user also has mental health problems, but the primary focus is on mental health.
Mind mental health carer workers	Based in Norwich, Great Yarmouth and King's Lynn. Little experience of providing support to substance misuse carers. The worker from Great Yarmouth Mind will liase with NORCAS.
Statutory agencies	
Statutory drug and alcohol treatment agencies	A range of agencies available to substance misusers across Norfolk. Very limited work with substance misuse carers.
Substance misuse social workers	Normally linked to statutory drug and alcohol treatment agencies. Provide limited support to substance misuse carers, can undertake assessments.
Primary Health Care	GPs and other primary health care staff provide some support to substance misuse carers. They do not appear to specifically include substance misuse carers in their Carers Registers.
Mental Health Support Service	Teams of social workers in Norwich, North Norfolk and Broadland. Provide some support to carers of substance misusers where the user also has mental health problems or where the carer has a mental health problem themselves.
Other mental health staff employed by Norfolk and Waveney Mental Health Partnership NHS Trust	Unknown, no information obtained except indirectly through carers. May provide some support to substance misuse carers where the user also has mental health problems or where the carer has a mental health problem themselves.
Mental health staff employed by the Queen Elizabeth Hospital NHS Trust	Unknown, no information obtained except indirectly through carers. May provide some support to substance misuse carers where the user also has mental health problems or where the carer has a mental health problem themselves.

4.13 Summary

- In total, 31 completed questionnaires were returned from 28 agencies in relation to support for adult substance misuse carers in Norfolk. The response rate was 61%.
- Half of the agencies did not identify any 'national or local standards or protocols' that they worked to.
- Others mentioned a wide range including the Norfolk DAAT guidelines, national QUADS standards, the internationally established 12 step pattern, local ACPC protocols and the Adfam standards, which were about to be published. Confidentiality, data protection and risk assessment procedures were also mentioned.
- There appeared to be little specific funding for carers of substance misusers and what was available was not established on a long term basis.
- The Carers Grant appeared to be primarily used by the general carers' agencies, which did not work with many substance misuse carers.
- Only six agencies were aware of any national or local research or reports on the needs of substance misuse carers.
- The agencies provided a wealth of information on the main issues faced by substance misuse carers, the effects of substance misuse on carers and the barriers to providing support to substance misuse carers. Many of the issues mentioned reflected the issues identified in national research, as outlined in Section Three.
- A third of the agencies indicated that they were aware that substance misuse carers are entitled to a Carers Assessment.
- Eighteen agencies identified gaps in current service provision. A number of agencies did not feel well enough informed to comment on this.
- Gaps identified included: carers' lack of awareness of entitlement to services, a need for support services that are dedicated to substance misuse carers, ring fenced funding for substance misuse carers, culturally specific services, a need for more therapy and more respite care.
- Suggestions to improve services related to the gaps were identified. They included more publicity aimed at carers, more specific and secure funding, more respite care, more trained staff and a change of public perceptions of what it means to be a substance misuse carer.
- Two thirds of the agencies had little or no awareness of other agencies or sources of support for substance misuse carers.
- Based on the responses to the questionnaire, telephone calls to agencies that did not respond and other information obtained during the course of the research, the support services available to substance misuse carers in Norfolk were summarised.
- It was concluded that the main sources of sustained support are the Linking Together Project in West Norfolk, NORCAS, the Matthew Project, and the self help support groups. There are seven Al-Anon Family Groups across the county for carers of people with alcohol problems but only three Families Anonymous groups for carers of people with drug problems. In cases of dual diagnosis, some of the support services for mental health carers also provide support to substance misuse carers. However the emphasis is usually on the mental health issues.

Section Five
The Adult Carers and their Substance Misusers

5.1 Introduction

This section provides information on the carers interviewed for the research and the substance misusers they cared for. It also presents the reported problems experienced by the substance misusers related to their substance misuse and whether they had a family history of substance misuse. This provides an indication of the complexity of issues faced by the carers

5.2 Background information on the carers

A total of twenty carers of substance misusers were interviewed. They came from six of the seven district council areas in Norfolk, see Chart 5.1. Despite additional advertising, no current carers from the Great Yarmouth area volunteered for interview. Half of the carers were from Norwich and therefore lived in a city. A third lived in a village or more rural area and the remainder lived in a town, see Chart 5.2.

The carers covered a wide range of socio-economic backgrounds. They ranged from people living on large council estates, some of whom were struggling to make ends meet, to those who were living in large detached houses in rural locations.

Most of the interviews were with women carers. Two interviews were with men and in two cases the mother and father of the substance misuser were interviewed together, see Chart 5.4. A third were in their fifties, a quarter were in their thirties and a further quarter were in their sixties, see Chart 5.4.

Despite specific advertising, only two carers of black or minority ethnic origin were interviewed. One was of mixed heritage and one had a traveller background, see Chart 5.5. In numerical terms this may be over representative of the number of substance misuse carers of black and minority ethnic origin in Norfolk, but it did not provide enough data to identify whether carers from different ethnic groups have particular needs or challenges.

Over half of the carers were caring for their son or daughter. A quarter of the carers were caring for their spouse or partner, all of these were women carers, see Chart 5.6. Two interviews were with grandparents and two interviews were with siblings of substance misusers.

5.3 Background information on the substance misusers

As part of the interviews, the carers were asked for background information about the substance misuser they cared for, details of their substance misuse and its impact on the substance misuser's life.

Over two thirds of the substance misusers were men, see Chart 5.7.

Approaching half (45%) of the substance misusers were in their twenties and a further 20% were in their thirties, see Chart 5.8.

Only one substance misuser was of black or minority ethnic origin, see Chart 5.9.

Charts 5.1 – 5.6 Background information on the adult carers interviewed

Chart 5.1 Location - District Council area

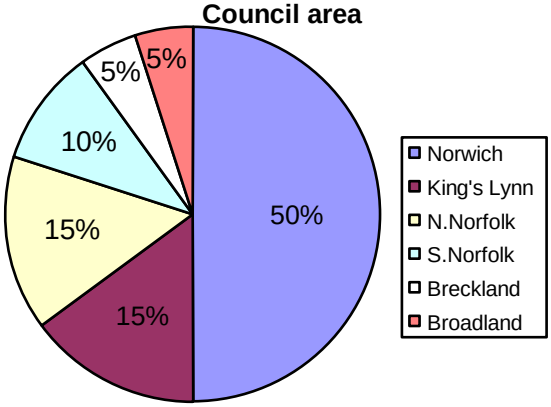


Chart 5.2 Location - type of area

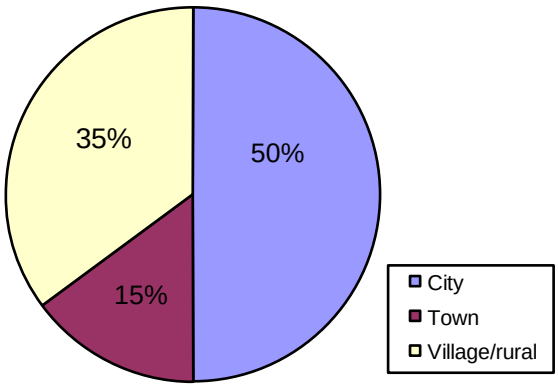


Chart 5.3 Gender

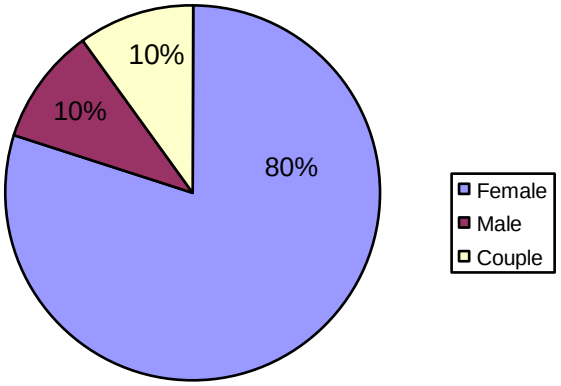


Chart 5.4 Age group

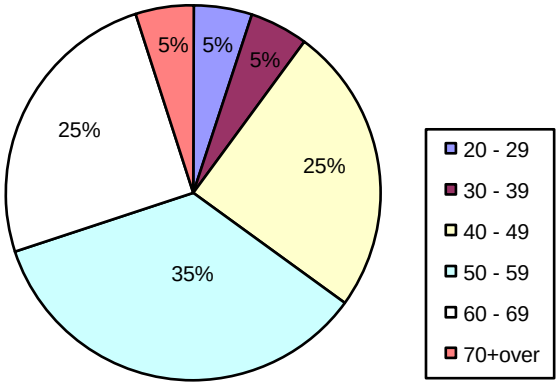


Chart 5.5 Ethnic background

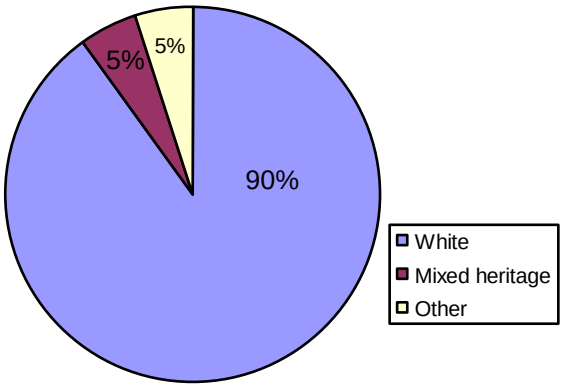
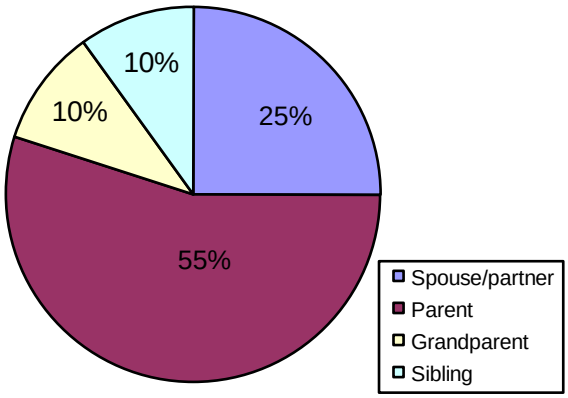


Chart 5.6 Relationship to the substance misuser



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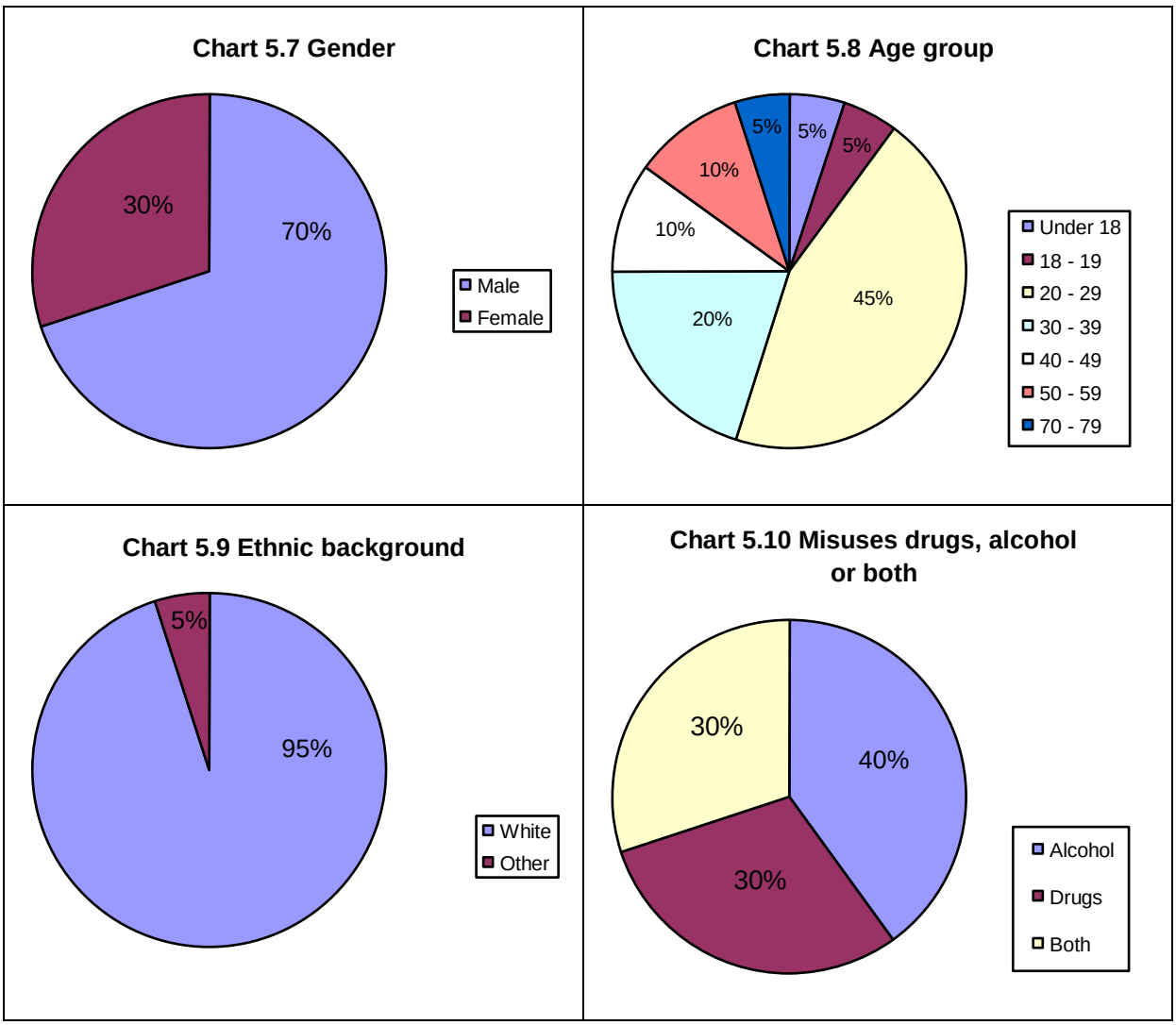
Charts 5.7 – 5.10 Details of the substance misusers cared for



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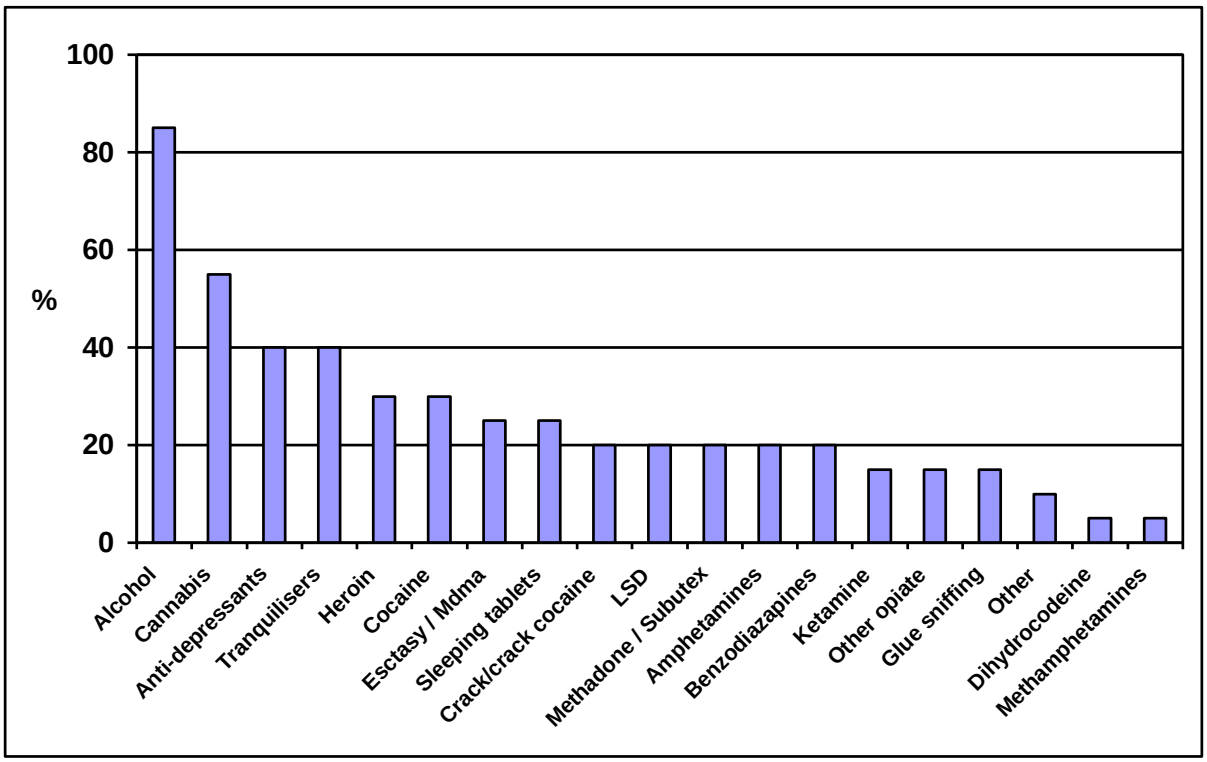
5.4 Details of their substance misuse

The carers were asked whether they had to provide care and support due to drugs, alcohol or both. Forty percent said that it was due to alcohol misuse, approaching a third (30%) said that it was due to drugs, and approaching a third (30%) said that it was due to both, see Chart 5.10.

When asked which drugs were used, the carers mentioned a wide range of substances. Chart 5.11 shows that 85% used alcohol, 55% used cannabis, 30% used heroin, 30% used cocaine and 20% used crack cocaine. Over two thirds (70%) of the substance misusers were poly drug users.

Chart 5.11 Drugs currently used



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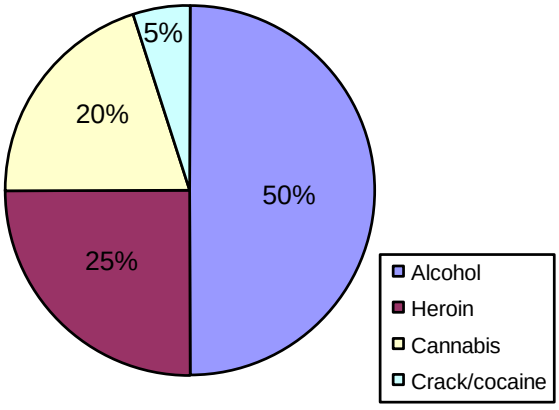
The carers reported that for half of the substance misusers alcohol was the main substance used, for a further quarter the main substance used was heroin, for a fifth the main substance used was cannabis. For one person the main substance used was crack cocaine, see Chart 5.12. Two of the people with alcohol problems were described as 'binge drinkers', as they did not drink all the time, but periodically.

Chart 5.12 Main substance misused



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Overall, thirteen of the twenty substance misusers were still actively using drugs or alcohol (four were using drugs, six were using alcohol and three were using both). Of the remaining seven substance misusers: two were alcoholics who were in recovery, one had stopped using drugs in the past three months, one had stopped using drugs and alcohol in the past six months, one had just come out of prison and was trying to avoid going back on drugs and alcohol. Two of the substance misusers had died some years ago, both of them had committed suicide.

The inclusion of carers of substance misusers, who were no longer actively using drugs or alcohol or who had died, provided some insights into the longer term effects of caring for substance misusers.

The carers provided further information on the substance misusers' drug and / or alcohol use. Some had used different drugs at different times:
'In recent years he has taken alcohol, cocaine, heroin, ketamine, methadone and tranquillisers. He has mixed ketamine in with the heroin. He has bought methadone on the street. He has bought and sold tranquillisers on the street. In the past he has also taken: amphetamines, anti-depressants, ecstasy when younger and cannabis.'
'She took glue when she was younger.'

Some had used drugs but now had an alcohol problem, others had used alcohol but now used drugs. Some used alcohol if they could not get their drug of choice.

Some people had been using drugs since they were at school. In some cases the drug use was accompanied by mental health problems:
'He started on cannabis when he was 16 and at secondary school. He was also on medication for his mental health.'
'She has been using cannabis for a long time. She started using cannabis at age 15 at boarding school. She then went to college where she took more drugs, I think she had a mental illness then, but it was not noticed or diagnosed. She probably kept on taking the cannabis as it alleviated her mental health problems.'

Most of the use of tranquillisers, anti-depressants and sleeping tablets was prescribed by the GP and was not identified as problem drug use. Only one or two people were identified as misusing prescribed medicines. One adult carer, who had also been a young carer, recalled that her parent had been addicted to prescribed medicines:
'I was also a carer for my mother when I was a teenager. She was taking Ativan. She attempted suicide many times during the time she was taking that.'

5.5 Problems experienced by the substance misusers related to their substance misuse

The carers were asked about eleven specific problems that the substance misusers might have experienced due to their substance misuse. This provided an indication of the problems that the carer might be dealing with. Chart 5.13 shows the proportion of substance misusers who were reported to have experienced each of the specific problems due to their substance misuse. All of the substance misusers had experienced at least two of the specified problems. Thirty percent had experienced at least ten of them.

Chart 5.14 shows the proportion of substance misusers who had experienced the eleven specific problems prior to their substance misuse. The proportion was 20% or less for all topics, except for emotional / mental health problems (35%) and problems related to education (25%). None of the substance misusers were reported to have experienced employment or housing problems prior to their substance misuse. Overall, 20% of the substance misusers had not experienced any of the specified problems prior to their substance misuse.

Many of the carers provided some details about the problems that the substance misusers had experienced.

Chart 5.13 Problems experienced by the substance misusers related to their substance misuse

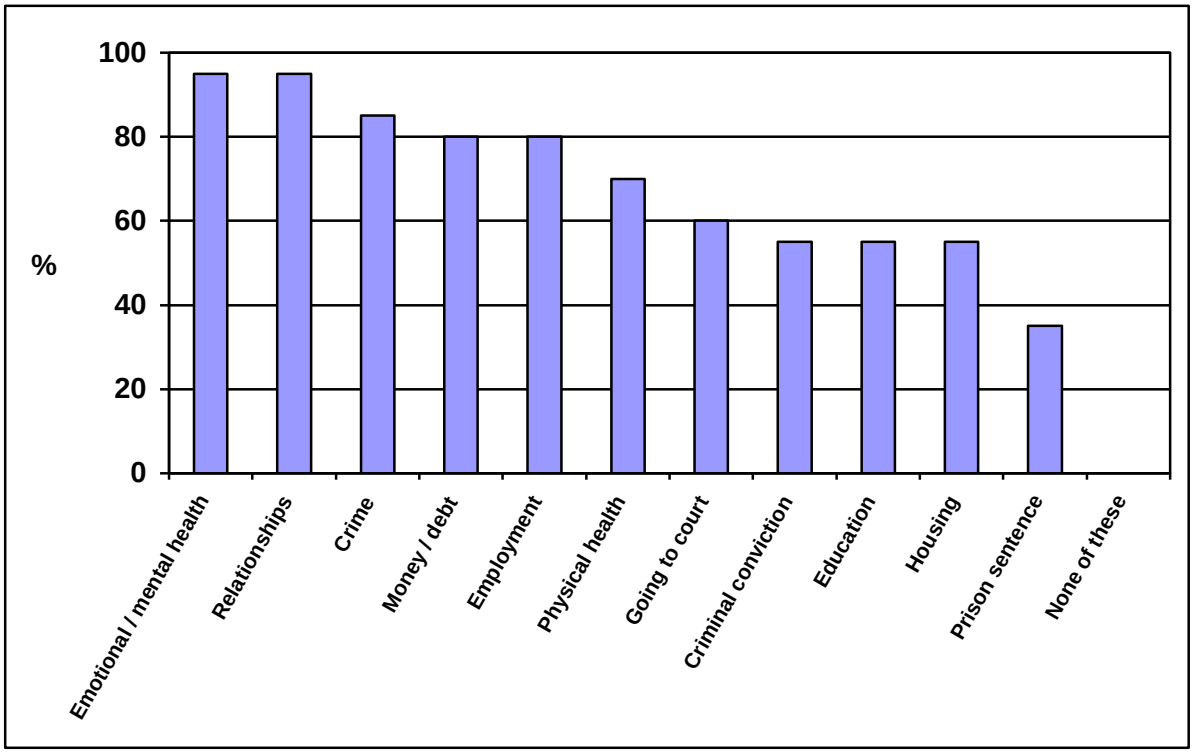

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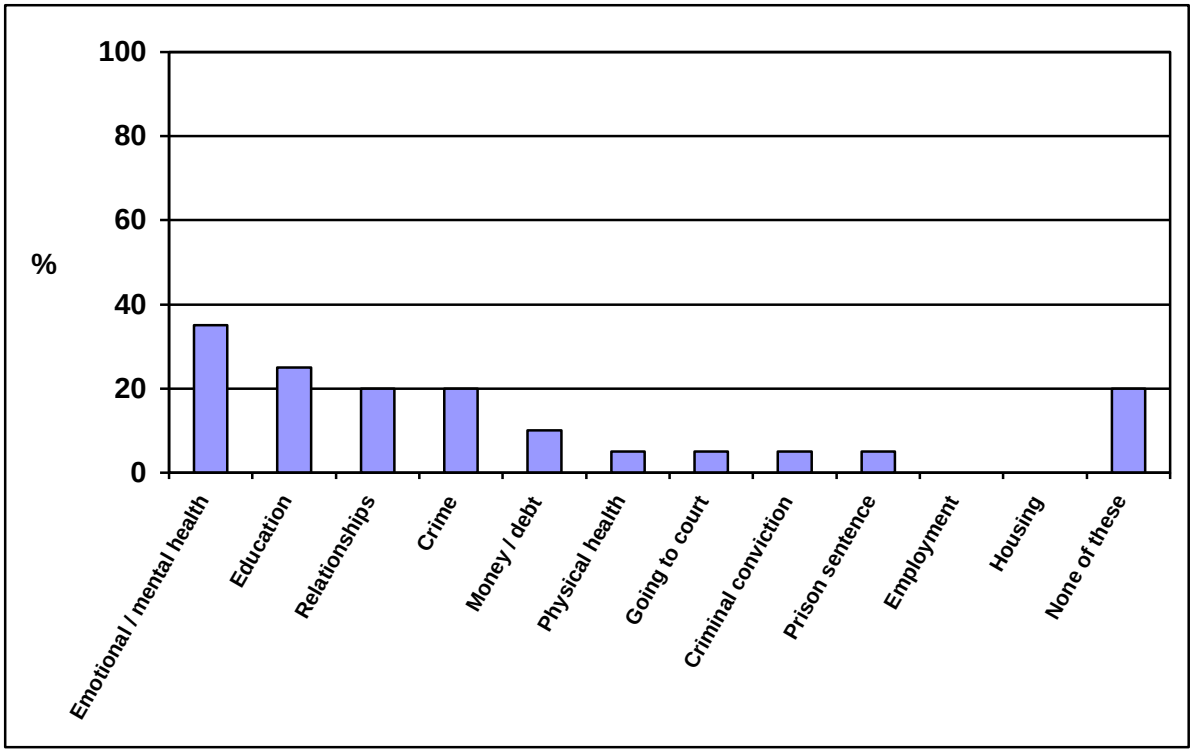
Chart 5.14 Problems experienced by the substance misusers prior to their substance misuse



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5.5.1 Emotional / mental health problems

The carers reported that 95% percent of the substance misusers had experienced emotional / mental health problems related to their substance misuse, see Chart 5.13. Prior to their substance misuse, just over a third (35%) had experienced emotional / mental health problems, see Chart 5.14.

A significant proportion of the substance misusers had officially recognised mental health problems. In some cases the carer thought that the substance misuse had triggered the mental health problems, in other cases they thought it was the other way round, others were not sure which came first:

'He has been diagnosed as schizophrenic. He went to [psychiatric hospital] in March last year but was psychotic before then. He took cannabis first and later became psychotic. He smoked enormous amounts. He buys it and then smokes it, from morning to night, until it is gone. It could have triggered the psychosis.'

'She has had mental health problems since she was a teenager. The doctors did not notice. They just thought she had adolescent problems. She was diagnosed as having schizophrenia when she was [in her twenties]. She is a 'revolving door' re her mental health problems. She has had two long stays in hospital and is now on her third. She took drugs before being diagnosed as mentally ill.'

'She is a manic depressive. She had mental health problems when she was a teenager, but we did not know what it was. She had problems with drinking since when she was 15 years. At 17 years she started cutting herself. She has been on a life support machine due to an overdose. They told her that it would not have happened if she had not been drinking. She went mad at them. She told them "I am not like this because I drink, I drink because I am like this".'

A number of the carers expressed frustration that they could not get the mental health problems tackled whilst the person was still using drugs and / or alcohol:

'Whilst he is using the drugs we can't get him assessed. We do not know if the drugs led to mental health problems or vice versa. It is quite likely that he has a mental health problem. We have tried to get him assessed for mental health problems. He saw a CPN, she said that when he was off the drugs they could give him something. I believe his mental health problems led to him taking drugs. When he was 14 years old, he was not on drugs, and he took an overdose of paracetamol.'

'There is an issue of dual diagnosis as she has mental health problems. The two go hand in hand. Alcohol affects the medication that she is taking. It has led to some brain damage and she has been in [psychiatric hospital] for a year. She has taken overdoses in the past.'

Neither of the two people, who had committed suicide, had been diagnosed as having mental health problems:

'I think he had mental health problems. Nothing was diagnosed. I think the drugs and drink damaged his reasoning capacity. I think he also had anxiety and depression.'

Approaching a third (30%) of the substance misusers had overdosed or tried to commit suicide. This is illustrated in some of the above quotes.

Some of the substance misusers were receiving support from their GP or a community mental health nurse (formerly called a CPN, Community Psychiatric Nurse):

'Emotionally he is a broken reed. He is having support from the doctor.'

'He is under a CPN due to depression.'

5.5.2 Relationship problems

Ninety five percent of the substance misusers had experienced relationship problems related to their substance misuse, see Chart 5.13. Prior to their substance misuse, 20% had experienced relationship problems, see Chart 5.14.

Some of the carers spoke about the person's relationships or lack of them:
'He had friends but not girlfriends because of the amount that he drank.'
'He finds it very difficult to form relationships because he wants to be friendly with people and forces himself onto them.'
'His drug use has affected his relationship with his friends. Once when he was high, he took a knife to one of his friends when the friend came to visit here. He does awful things and buys friends, he buys cocaine for a group of friends. Several of his friends have avoided him as he offered them drugs when they were trying to come off drugs.'

5.5.3 Money problems or debt

Eighty percent of substance misusers had experienced money problems or debt related to their substance misuse, see Chart 5.13. Prior to their substance misuse, only 10% had experienced money problems or debt, see Chart 5.14.

Some people owed thousands of pounds:
'He used to have money and a nice home. He blew it all on drugs. He has had the bailiffs around a lot. The bailiffs said that they were coming to my home to take things.'
'He had a lot of debt. It ran into many thousands of pounds. Some were drug debts and others were credit card debt that he used to buy his drink.'

One person said that the substance misusers that she cared for did not have money problems as:
'[She] used to earn money through sex work and [he] used to steal money.'

5.5.4 Employment problems

Eighty percent had experienced employment problems (losing a job or not getting a job) related to their substance misuse, see Chart 5.13. Prior to their substance misuse, none of the substance misusers had experienced employment problems, see Chart 5.14. Some of the substance misusers had never worked and others had lost their jobs. The latter was sometimes due to drink driving convictions.

5.5.5 Physical health problems

Seventy percent had experienced physical health problems related to their substance misuse, see Chart 5.13. Prior to their substance misuse, only 5% had experienced physical health problems, see Chart 5.14. A variety of physical health problems were mentioned. They included: an ulcer, kidney and liver problems, gastritis, vomiting, palpitations, sleeplessness, incontinence and hepatitis C.

5.5.6 Education problems

Fifty five percent had experienced education problems (stopping school, university, college or studying) related to their substance misuse, see Chart 5.13. Prior to their substance misuse 25% had experienced education problems, see Chart 5.14.

Cannabis use was the main reason for school or university work being affected:
'He did very well with his GCSEs, he got 11 of them, but then he was affected by cannabis.'

One person, who missed out on his education, was now studying:
'He stopped going to school and never went to college. He became a [craftsman]. He has been studying in prison and has now started a college course.'

5.5.7 Housing problems or homelessness

Fifty five percent had experienced housing problems related to their substance misuse or had been homeless, see Chart 5.13. None of the substance misusers had experienced housing problems or had been homeless prior to their substance misuse, see Chart 5.14.

Housing problems included:
'Wherever he goes he is thrown out because he can't handle it and others can't handle him. I provided housing for him and he nearly burnt it down.'
'At one time he was homeless and sleeping on the streets.'
'He was in the army which provided his accommodation and then he was [in a job] with a tied house. When he was afraid his employers would find out about his drinking, he would move jobs and therefore house.'
'When he came out of prison the first time he had a housing problem. He went and lived with a neighbour of mine who has alcohol problems. My son had no help with his accommodation, he only had his Probation Officer. His accommodation was not looked into as my son said that he was OK. I said that that he was not, because he was with a person with a drink problem. Then he re-offended and went back to prison. This time the CARATS team in the prison have sorted out a supported group home for him.'

5.5.8 Involvement with the criminal justice system

Eighty five percent of the substance misusers had been involved in crime related to their substance misuse, see Chart 5.13. Prior to their substance misuse, only 20% had been involved in crime, see Chart 5.14.

Sixty percent had gone to court due to crime related to their substance misuse and 55% had received a criminal conviction, see Chart 5.13. Prior to their substance misuse, only 5% (one person) had gone to court due to crime prior to their substance misuse and 5% had received a criminal conviction, see Chart 5.14.

Thirty five percent had received a prison sentence for crimes related to their substance misuse, see Chart 5.13. Prior to their substance misuse, only 5% (one person) had received a prison sentence for crimes, see Chart 5.14. This person had not had any drug problems until he was introduced to heroin whilst in jail.

Some convictions were for drug offences, burglary or violence against another person and some had led to a prison sentence:
'He did burglaries and has been in prison.'
'Lots of crime. The most serious were trying to take drugs into prison and threatening a boy with a knife.'
'She has been violent. Mental illness or drugs have led to her becoming violent. When I refused to give her money she knocked me down. She has threatened the neighbour's child with a knife.'
'He went to the Colchester Detention Centre for fighting when drunk when he was in the army. He has smashed windows when he was drunk. Last Friday night he cashed his giro and went out drinking and was arrested for assault of a police officer.'

Some offences were related to drink driving:
‘Drink driving, he got banned for a year. He was not actually driving. He was asleep behind the wheel in a car park, completely unconscious.’

Some offences appeared to be relatively minor:
‘He stole cigarettes from a garage when he lost his job there.’

5.5.9 Other problems experienced by the substance misusers related to their substance misuse

The carers also identified other problems that the substance misusers had experienced related to their substance misuse. These covered a range of different problems, including violence from drug dealers and involvement with sex work:
‘He has had some problems from dealers. He owed them some money and they beat him up, they beat him up seriously. The dealers have also called round here wanting money.’
‘It is also a worry in that she is a sex worker and so can get into some dangerous situations.’

Two of the women substance misusers had had their children taken into public care by social services. Two other women substance misusers had an eating disorder, one was binge eating and the other was anorexic.

5.5.10 Other problems experienced by the substance misusers prior to their substance misuse

Only one carer stated that the substance misuser had had any other problems prior to their substance misuse. However, a number of other issues emerged during the interview:
‘He had a very difficult childhood. His father was an alcoholic. His father was physically and verbally abusive. He beat him and stabbed him. At 14 years he went [to sea] and became a missing person for four years.’
‘We found out that her father had sexually abused my other girls, who were not his children. When she found out what her father had done, it all got muddled up with the drinking. He says that he did not sexually abuse her and she cannot remember. We always thought that there was something because she started fainting and having anxiety attacks when she was three years old. We do not know if it was related to her mental health problems or caused by the abuse. We will never know.’
‘His drinking always happens after he has had contact with his mother. We tried not having any contact with her. He comes from a very unstable family home. His parents lived in Africa and the children went to boarding school. Nothing was discussed in the family.’
‘She was living in a household where she was also a carer when she was young.’
‘He had unspecified special needs and learning difficulties when he was younger, and still has them. The problem is that he has no sense of responsibility about paying bills etc.’

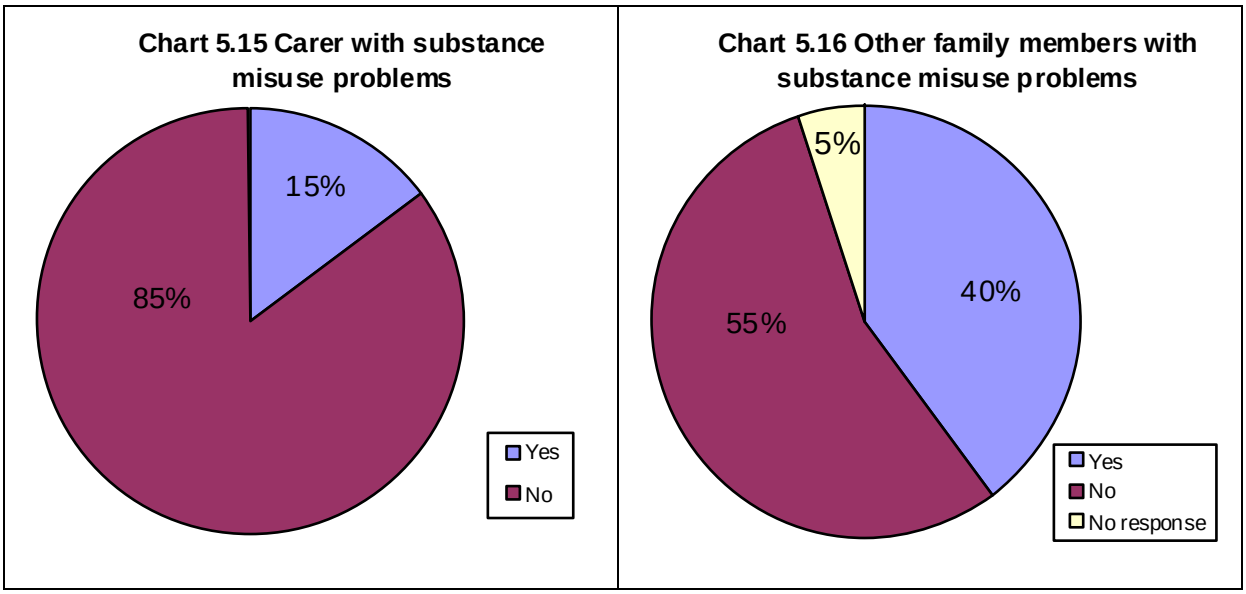
One substance misuser had been taken into public care by social services as a child:
‘She went into care when she was 11 years old. This was because when she was 10 she came home and said that she had been raped, but her mother did not want to know, so she just went out and became a sex worker…. I had to get her into care because she needed protecting. Her mum was not coping.’

One carer talked about the stillborn death of her daughter, which she felt had contributed to her husband's drinking:
'We lost a child, she was stillborn, she would be 21 years old this year. I get down about it, but it happened, and you just have to get on with it. He still gets upset and wants to drink. It was always near her birthday, when he got worst and got depressed and drank. When you lose a child the focus is on the mother. I went to pieces, he was so strong. No one thinks of the dad and his need to grieve.'

5.6 Family history of substance misuse

The carers were asked whether they or any other family members had had any drug or alcohol problems. This provided some evidence of inter-generational substance misuse. Fifteen percent of carers (three people) reported that they had had drug or alcohol problems themselves, see Chart 5.15:
'I have had problems with drink in the past. I used to self medicate with drink when I got depressed.'
'I have tried them. I have tried a lot of things but it wasn't a problem as I like to be in control too much.'

Another person, who had not had any drug problems, said:
'No, but I used to smoke cannabis occasionally myself in the past, in the 1970s. It was lovely.'



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Forty percent of carers reported that other family members had had drug or alcohol problems, see Chart 5.16. Some people reported quite a strong family history of substance misuse, usually of drinking rather than drugs. This was not restricted to those living in socially disadvantaged areas:
'My great grandmother was an alcoholic. My brother was an alcoholic, but he reformed. My father drank, I don't know if he was an alcoholic, but he never said no to a drink, and it altered his personality.'
'My husband had a sister who was alcoholic and his father was possibly an alcoholic, he was definitely a heavy drinker. It was part of the ethos of the whole area – my husband came from a Scottish mining family.'
'Both my husband's parents are alcoholic, but do not admit to it. My husband's brother died from drugs and alcohol in his twenties. My husband's aunt (his father's sister) and his cousin (his aunt's daughter) are also alcoholic.'

Some of the carers commented on siblings or the next generation taking drugs:
'Another of my grandchildren also had a drugs problem, he was using heroin. His parents could not cope because he was robbing them big time. So they kicked him out and he also came and lived with me. He did a little stealing from me. He has stopped using drugs now.'

Some pointed out that it was under control:
'My other son does drink too much and smokes tobacco and cannabis, but it is controlled use.'
'My children have only experimented a little.'

5.7 Summary

- Twenty adult carers were interviewed.
- The characteristics of the carers interviewed reflect those carers who were willing to come forward to participate in the research, rather than being a representative sample of all substance misuse carers in Norfolk. In particular, the age range of the carers may not be representative of carers of substance misusers.
- However the carers, and those whom they cared for, did represent a range of socio-economic groups living in different circumstances across most of Norfolk. The carers included parents, siblings and grandparents of substance misusers. The substance misusers encompassed those with drugs and/or alcohol problems and people at different stages in their substance misuse / recovery.
- Some of the carers interviewed were able to reflect on what it had been like when they had been providing more intense care, whilst others were in the midst of caring at the time of the research.
- The carers reported that the substance misusers had experienced a wide variety of problems related to their substance misuse. This demonstrated that the carers were facing complex problems.
- Over 80% of the substance misusers were reported to have had problems with their emotional / mental health, relationships, crime, money / debts and/or employment.
- A smaller, but significant, proportion were reported to have had problems related to their physical health, education, housing and/or been involved with the criminal justice system, including time spent in prison.
- In addition, two substance misusers had been involved with social services in relation to the care of their children and two had been involved in sex work.
- Although none of the carers interviewed had current substance misuse problems themselves, in some cases there was evidence of a family history of substance misuse. This was not restricted to those living in socially disadvantaged areas.

Section Six
Caring for Substance Misusers

6.1 Introduction

This section presents information on the carer's role in supporting the substance misuser, whether they considered themselves 'a carer' and the effect of caring for the substance misuser on the carer and the wider family.

6.2 Details of the caring situation

Chart 6.1 shows the length of time that the carer had been caring for the substance misuser. Half had been caring for five years or more, 20% had been caring for two years but less than five years and 20% had been caring for less than two years. Those who had cared for people for over ten years were more likely to be caring for people with alcohol problems, but some carers had provided this length of care for people with drug problems.

Some had been providing care on a regular basis for many years, others had been providing more intense care at certain times:
'Since we have been together, over 30 years.'
'On and off over the years. He has married twice and both broke down due to his alcohol use. We provided care and support between his two marriages and now, following the end of his second marriage.'

The substance misuser was not currently living with the carer in 45% of cases, approaching a third were living with the carer and a quarter sometimes lived with the carer, see Chart 6.2.

Chart 6.1 Length of time cared for the substance misuser

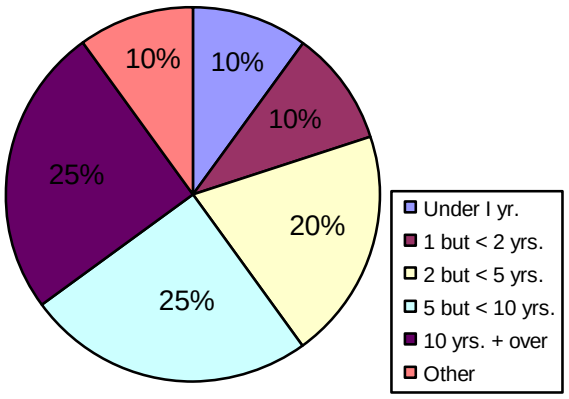
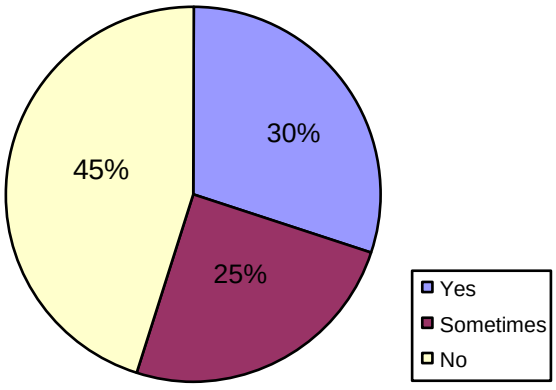


Chart 6.2 Currently lives with the substance misuser



n = 20

6.3 Type of care and support provided due to the person's substance misuse

The carers described the type of care and support they provided to the substance misuser, due to their use of drugs and / or alcohol. The key activities mentioned were providing emotional support and being there to help the substance misuser. This included providing money and financial support, domestic support to those living with them (washing, cooking, cleaning), doing or helping with shopping and providing food or meals for those not living with them, making appointments and accompanying them to appointments. Other activities mentioned were monitoring their medical

needs, supervising their medication, providing housing, providing transport, taking them out and dealing with letters:
‘Everything really. Housing, laundry, take him places, watch over his medical needs. I protect him. He takes up a great deal of my time. It is always there. He phones me most days. He always wants something. I feel unable to retire and start a new life anywhere.’
‘I have to help him out with money and just be there for him. His giro is sent here because he does not pay his bills. I take him shopping.’
‘I provide him with a food parcel every week, with five meals in it.’
‘She was needing a lot of money. She was wanting between £30 and £40 a week for things for our great granddaughter. She does not have the support of her parents. She would spend a lot of time talking to my wife.’
‘Not so much now, he has been off the drink for a long while. In the past he’s had incontinence. Now I’m just there for him. I am his battering thing when he gets down and loses his temper. In the past, well anything really, like getting him to bed, toilet and in and out of the bath. It just becomes a way of life, you do not stop and think what you are doing, you just do it. He made me very ill.’

Some people needed to provide close supervision when the person was under the influence of drugs or alcohol or trying to give them up:
‘She binge drinks. I have to be there then because it leads her to self harm – she overdoses, cuts herself, spills things, breaks things, falls over and collapses in heaps. I make sure that she does not choke. She normally drinks at home. When she was with her husband she used to do it outside the home.’
‘I would spend a lot of time talking to him. I would be caring for him when he did cold turkey at home. I would go and stay with him…..You would just have to watch over him for two or three days.’

Some women had become the main breadwinner for the family due to their partner’s substance misuse:
‘I provide emotional support and support for the rest of the family. I have to work full time because he is not able to work and bring in a full wage. …..I therefore have the pressure to carry on working to pay the bills.’

Two people had taken on the care of the substance misuser’s child or children:
‘I provided my granddaughter with a roof over her head and looked after her baby. I worked with social services so that her baby would not be taken into care by other people. The baby was officially in my care.’

One person, who cared for a binge drinker, reported:
’When he has been drinking he usually comes back in a terrible state or I go and rescue him. Before he lost his job, they sent a private detective out to find him. After he lost his job, I became the private detective. You fix everything. You lie to his employers. You live with the shame of it. When he is well, he is able to go to work and everyone loves him.’

Another person pointed out:
‘It is difficult with alcoholics to provide physical care. It is so hidden. There is so little understanding of substance misuse. People often ask why the carers just don’t leave. It doesn’t work like that. There is a constant pressure to keep it all normal.’

6.4 The main problems experienced by carers of substance misusers

The carers identified the main problems experienced by carers of substance misusers. Some spoke about their own situation, others referred to carers in general. They referred to the emotions they had to deal with and practical issues. The main problems identified were stress, fear, isolation, frustration and anger, difficulties with obtaining information and support, issues related to confidentiality and financial worries.

Comments on stress and isolation included:
'You are constantly on edge. You never know what you will find. You are constantly watching them.'
'Keeping it all even. Keeping the peace. Keeping the unit together. When he comes home drunk, he is abusive, nasty and arrogant or he is sad and maudlin.'
'Having someone to talk to about it. It is a private illness. We only told our friends recently when he came back to live with us. We did not tell them for twelve years.'

For carers of substance misusers with mental health problems there were particular issues related to confidentiality and treatment. This was sometimes accompanied by frustration and anger:
'Frustration is the main thing. There is a lack of support. There are issues around confidentiality. Statutory services will not talk to us. He is no longer regarded as a child but an adult with free will. This is despite being on drugs, medication and because of having a psychiatrist. To us it seems wrong. He is regarded as independent yet he is treated because he is not independent. He has been sectioned several times. He is able to hold a lease yet he needs support to live alone. This is all very frustrating.'
'When he was living with me and was psychotic it was fear, I could never do anything right. If I went out, he was agitated and full of questions about what I was doing. I got a mobile phone, when he was psychotic, so that I could go out and make phone calls in town. If he heard me on the phone he would go berserk. Now I am a distant carer as he is living in a secure mental health unit. Now the issue is not getting information. I need to find out what I can and can't know. I have recently obtained a leaflet about carers and confidentiality issues.'
'I feel fear for his physical and mental health and future. I am angry with him, disgusted and disappointed. Fear is the main thing. I fear for the rest of the family, especially the younger children. The rest of the family reject him. They think it is dirty and immoral. You think: "What have I done wrong?" I am angry that, in my opinion, public services can't take responsibility for saving a person like him from himself.'

Comments on financial worries included:
'I worry about him first and then the money. The money is a main thing, especially if you can't work yourself.'

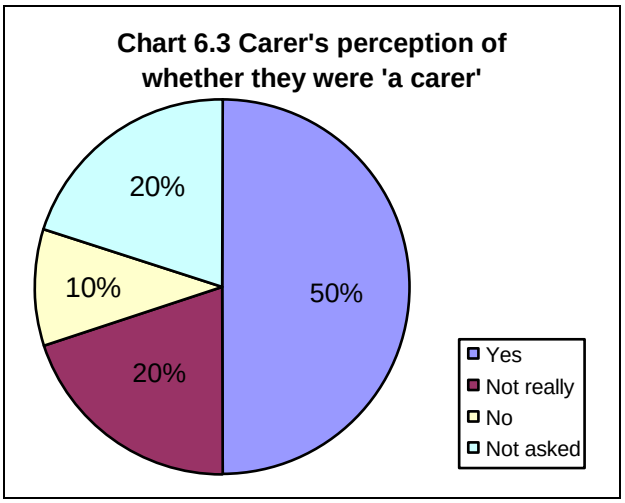
Comments on lack of information included:
'There is a lack of understanding. We did not know what we were dealing with. We did not know about addiction. We did not realise the problems or realise the mental processes. We were worried about his safety.'

Comments on difficulties in finding support included:
'Finding out who you can turn to, who will listen to you. I banged my head against a brick wall for three years.'

Other comments included:
'The situation leads you to becoming partly criminal yourself, because you lie, cheat and deceive for them. You become a party to it.'

6.5 Perceptions of being a carer

When asked whether they saw themselves as 'a carer', half of them said that they did, 20% said 'not really' and 10% said that they did not, see Chart 6.3. (20%, were not asked this question). This is possibly higher than for substance misuse carers in general, as many of those interviewed were contacted through agencies.



n = 20

One person pointed out:
'We are the only people he has got. We are his 'stopgap'. If we were not here God knows where he would be. He has no money. I agree that we are carers – that is what we do.'

Some were able to pinpoint when they first became a 'carer' for the substance misuser:
'I became a carer for my son eight years ago because everyone rejected him. I was the only one interested.'
'When his marriage split up and he came to stay with me. She kicked him out – they were both as bad as each other – they were both on drugs, she was using cocaine and he was on heroin.'
'After 20 years, when I thought of leaving him and I realised there was no one else who would look after him. But then as a wife your job tends to be as a carer.'

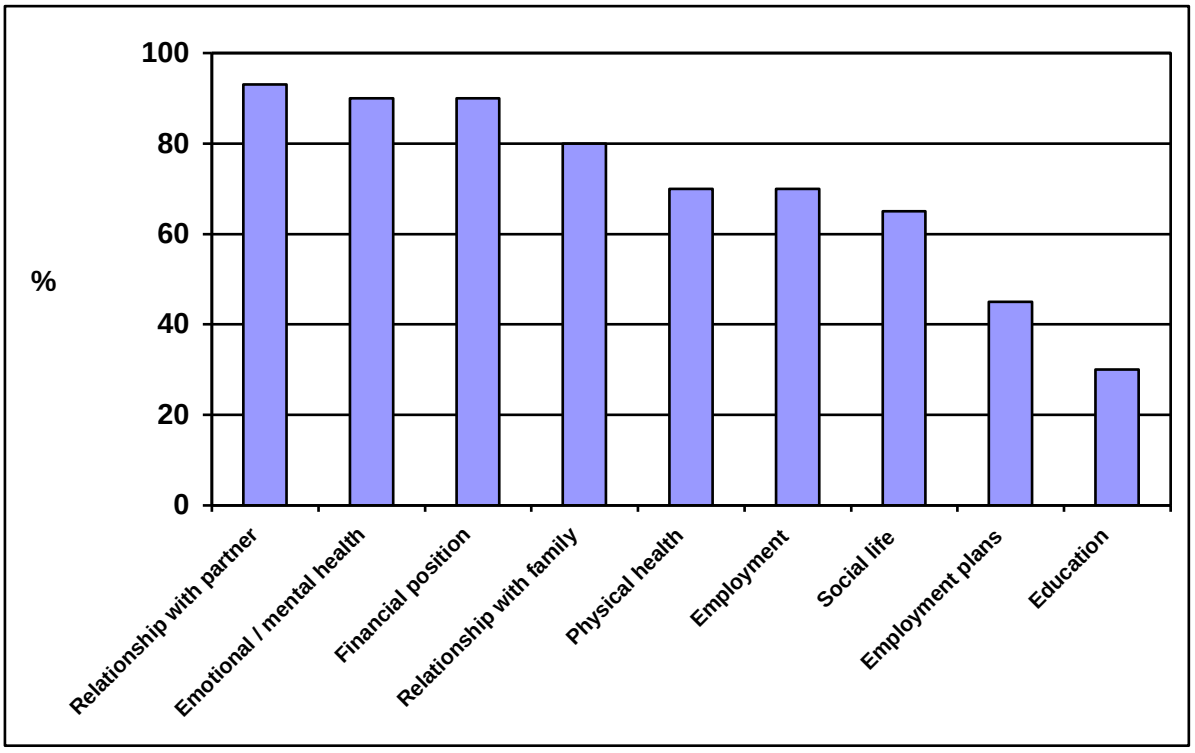
Some people only saw themselves as a 'carer' when they were told they were:
'[My support worker] told me that I was his carer. But, as he is not living in my home, I don't really see myself as his carer. I find the word 'carer' difficult in this context. I have helped him with what he would let me help him with. There were lots of things he would not let me help him with. I just had to walk away. It was his decision.'
'Yes, but only for the last two years, since I became involved in the [carers group]. Before that I did not know that there was such a thing as a "carer".'

Others were very clear that they did not see themselves as a 'carer':
'I do not identify myself as a carer. I am not a label. You do what you have to do.'
'No, I am just her mum.'

6.6 Effect of the drug / alcohol use on the carer

The carers were asked about nine specific aspects of their lives that might have been affected by caring for the substance misuser. Chart 6.4 shows the proportion that said the person's substance misuse had affected these aspects of their life.

Chart 6.4 Effect of the substance misuse on the carer



For 'relationship with partner' n = 14, for all others n = 20

6.6.1 Effect on the carer's relationship with their spouse or partner

Ninety three percent of the fourteen carers with a spouse or partner reported that the person's substance misuse had affected their relationship with their spouse or partner, see Chart 6.4.

Not surprisingly, where the spouse or partner was the substance misuser, this had normally had an adverse effect on the relationship:
'We are not as close as we were. The love is not there from my side as it was. I supported him this time, through his third detox, but I won't do it anymore.'
'I have left a few times. I now have this flat of my own. She is like two different people, one when she is sober and another when she is drunk.'

Where the substance misuser was a child of the carer, the effect had been mixed:
'My first husband told him to go to hell, he has not lifted a finger to help him. With my second husband it has had a positive effect. He has given me and my son the most tremendous support.'
'As good as he is he can occasionally get angry about it. It is difficult for him at times yet it is also easier for him to say "No". He can act as a gatekeeper if she is being too demanding. He is amazingly supportive.'

‘My partner is horrible to him and says that he is a waster. My partner says that he won’t have my son in the house. He resents the attention that I spend on my son. I feel pulled in different directions.’

6.6.2 Effect on the carer’s emotional / mental health

Ninety percent of the carers reported that the person’s substance misuse had affected their emotional / mental health in some way, see Chart 6.4.

A couple of the carers stated that they had had mental health problems prior to the person starting their substance misuse:
‘No. I had mental health problems before my son’s drug use, so I do not blame that on him. It has not affected my mental health because I have had a lot of support. It could do though, if you let it. I’m sure it does affect me mentally but I am on medication, which keeps me stable.’
‘I am a depressive. This was since he was 16 years old. His drug use has made it worse. I have been frightened of him and this has led to a situation that I could not cope with.’

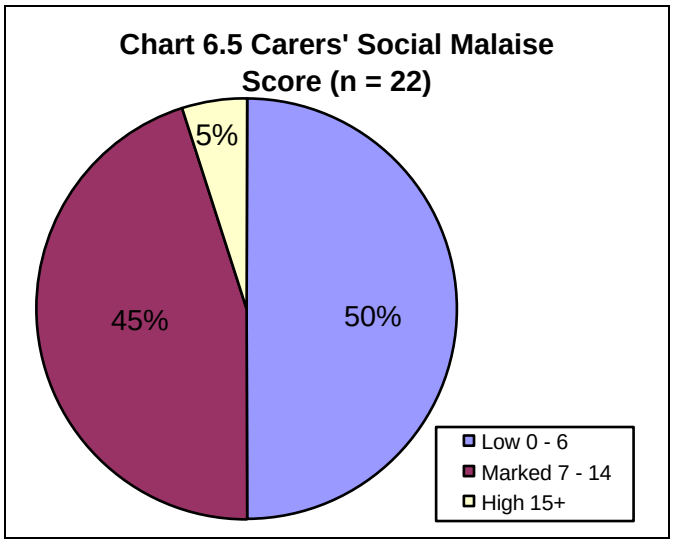
Some carers stated that they had been on anti-depressants in the past or been in a psychiatric hospital and some had until recently had a community mental health nurse (formerly a CPN). Some carers were currently on tranquillisers or anti depressants.
‘I was on Prozac myself for many years. There are so many pressures on me.’
‘Yes big time, I am on anti-depressants.’

Most of the carers reported that the substance misuse had created worry, fear and stress:
‘I am shattered, my nerves are caput. I was walking on eggshells when he drank. I was frightened to say anything when he drank. He made me feel completely worthless, everything was turned round to my fault.’
‘Yes, he dominates my thinking day and night. I can’t sleep. I wake up in the night if there is a problem.’
‘I get depressed when she is like this. But I am trying to ignore it so that I don’t.’
‘I am scared all the time and live on a knife’s edge all the time. At night I turn off the mobile phone and the house phone so that I know I can go to sleep and not worry about the phone going off.’

6.6.2.1 Social Malaise Inventory and levels of emotional stress

In order to measure the carers’ emotional stress levels, all carers interviewed (22 people, including those who were interviewed as a part of a couple) were asked a series of questions using the ‘social malaise inventory’ (Rutter et al., 1981). These are a series of questions with ‘yes’ or ‘no’ answers. The range of possible scores is from 0 to 24. A score of 0 to 6 indicates a ‘low’ emotional stress level, a score of 7 to 14 indicates a ‘marked’ emotional stress level and a score of 15 to 24 indicates a ‘high’ emotional stress level.

The range of the scores for the carers was from 2 to16. The average score (mean) for the carers as a whole was 7.09. A score of 7 is the conventional cut off for possible psychiatric disorder. Half of the carers were at this level or above, see Chart 6.5.



The figures were examined in greater detail. Half or more of the carers said 'yes' to five of the individual questions, as follows:

- Do you often get worried about things? 82%
- Do you feel tired most of the time? 64%
- Do you usually have great difficulty in falling asleep or staying asleep? 64%
- Do you often have backache? 54%
- Do you often feel miserable or depressed? 50%

Approaching a third, 32%, said 'Yes' to the question: 'Have you ever had a nervous breakdown?' A further person was not sure, but had experienced considerable grief when the substance misuser had died.

The 25% of carers with the highest scores (scoring between 11 – 16) were all people caring for people with alcohol problems. How far this would be true of a larger sample of substance misuse carers is not known.

6.6.3 Effect on the carer's financial position

Ninety percent of the carers reported that the person's substance misuse had affected their financial position, see Chart 6.4.

Partners of substance misusers reported general shortages of money:

'We often did not have enough money for essentials, although we managed. He was never in a high wage employment, but he was in a management position in the end. His boss knew that he drank, so rather than give him a pay rise he put extra money in his pension. His boss was a very clever and caring man.'

'Yes, with both of us working we should have had a better lifestyle. Recently, the nature of his work and irregularity of the work has had quite a bad effect on our financial position.'

Some parents reported that they had extra costs due to supporting the substance misuser in their daily living or in paying off past debts, including drug debts:
'It was OK when I was working, I was earning good money. Now I am on a pension. She buys the drink with her own money, but she binge eats and eats her way through the fridge. Plus I have to replace things that she has broken.'
'Food parcels and we are starting to pay off his bills, as he had not paid anything for two and a half years. We have given money to placate people – a down payment and now weekly payments towards paying off the bills. Some people we paid instantly to avoid repercussions. My husband paid off a drug dealer to keep my son away from him.'

In other cases the substance misuser stole or cheated the carer out of money:
'Yes, due to him stealing from me.'
'In the past he took out a loan in my name and, with the help of a girl, used my credit card. He created £3000 worth of debts in my name.'

Some parents appeared to be subsidising their child's substance misuse:
'I give him lots of money, lots, lots, lots. I subsidise his lifestyle, which is terrible.'
'We have given him thousands of pounds – probably a total of £20,000 in four years. He is still asking us for money. People say "Do not give it because it is just killing him." The worst thing is not knowing how to handle it ever, what to do for the best.'

Another carer reported:
'No, I will not, and have never, given her money. I would give her food but not money. That is why she probably does not contact me every day of the week.'

6.6.4 Effect on the carer's relationship with other family members

Eighty percent of the carers reported that the person's substance misuse had affected their relationship with other family members, see Chart 6.4.

Comments related to the relationship with the carer's children and other family members, who sometimes acted to protect their own children. Christmas and other family times could be particularly difficult:
'My daughter resents the care I spend on my son.'
'It is difficult in the family. When she was [younger], my son did not want her to have medication for her mental illness. He was so angry that he left the country.'
'They were pretty good but they used to take it out on me because I took my grandchildren in. But at the end of the day they were still family. One of my children stopped me from seeing my other grandchildren, as they did not want to bring them to the house.'
'It is hard at Christmas as I did not want her to see much of my family. It was embarrassing. I was also feeling guilty. I could not rely on her not to start drinking if it was around.'

Some carers had received quite a lot of support from other family members or had not let the substance misuse change the relationship with them:
'They all know, they are all quite supportive.'
'No. They have done all they felt they could do. They are not really actively involved. My dad has helped financially, my mum has listened when I am upset and my other son has offered support. My son really upset his granddad, but no-one has rejected him. They have been a bit scared when he has been invited to family events.'
'No, I am close to all the children and grandchildren. When he was drinking he was very, very jealous of that, but I would not let him spoil that.'

6.6.5 Effect on the carer's physical health

Seventy percent of the carers reported that the person's substance misuse had affected their physical health, see Chart 6.4.

Some of the carers had been physically attacked by the substance misuser:
'My daughter has kicked me a couple of times and cut me with a knife.'
'I have also been attacked by her, once when I was pregnant.'
'I have had both physical and verbal abuse. I have had to get new glasses on one occasion.'

People felt tired and worn out with the constant worry:
'I am exhausted, it can be very, very tiring caring for someone. If you have an adult child with these problems, you feel you can't get on with your life, because you have got to be there to pick up the pieces.'
'Doing stuff for them and thinking for them is draining.'

Others had physical symptoms, which could have been related to stress:
'I have migraines. I am waiting to see a neurologist about my migraines. I do not know if they are due to my husband's drinking. I also have panic attacks and do not sleep well.'
'Headaches, sleeplessness.'
'When I get stressed I experience physical pain in my arms.'

6.6.6 Effect on the carer's employment, or employment plans

Seventy percent of the carers reported that the person's substance misuse had affected their employment, or their employment plans, see Chart 6.4.

Some carers had given up work, changed jobs and / or reduced their income due to the substance misuse:
'I was a teacher and I retired early, partly to take care of my son.'
'I got made redundant and was going to get another job but then decided that I could not. I used to work nights and when I came home the inside of the house looked like someone had been murdered.'
'Both me and my sister gave up our jobs to look after him.'

Some people had changed jobs and / or taken on more work to increase their income:
'I used to be a nurse. I was a good nurse. In the early years I did endless night shifts to pay for his drink. When I was nursing I used to moonlight for Marie Curie to pay for his drinking. But it just fuelled his drinking. When my husband lost his job, I got a [different type of job]. I hated it. I had to put on a smile for everyone, as if everything was all right, when it wasn't.'

Carers also reported that the substance misuse had affected their performance at work:
'Once when I was at work my husband rang me and I broke down crying and they took me home.'
'I have had to take time off because she was in hospital.'
'I had to stop work at one point as it was all getting too much for me. They were very supportive and I was able to get a job back later.'

6.6.7 Effect on the carer's plans or wishes for their future employment

Forty five percent of the carers reported that the person's substance misuse had affected their plans or wishes for future employment, see Chart 6.4.

Some wanted to get back into work but had been held back:
'If I can sort out my migraines I would like to go back to work. My son encourages me, but I can't concentrate. I went into "New Deal" but I was getting the migraines so could not commit to working.'
'I am looking to go back onto some courses in the future. I want to finish the courses first. Not doing the courses has set back looking for my own paid work.'

Some were not well enough to work, some were retired or moving towards retirement or were not looking for a change:
'I am not well enough to work.'
'I will now stay here until I am retired, as I am in my 50s.'

6.6.8 Effect on the carer's social life

Sixty five percent of the carers reported that the person's substance misuse had affected their social life, see Chart 6.4.

Deciding whom to tell about the substance misuse could be very difficult for some people:
'We have been damaged by the cruel gossip in the village. We have had to learn to let it go. I told the GP and one person about my husband drinking and it got out in the village and was very damaging. I do not mix with people in the village.'
'It's embarrassing, neighbours always know, it's very embarrassing because there is obviously something wrong with him.'

The substance misuse limited the carers' social activities for a number of reasons. These included: the need to be available for the substance misuser, the behaviour of the substance misuser in social situations and lack of money:
'I would not know if I could go out. He might turn up and I would not be there for him.'
'You can't go out without worrying. Holidays have been affected and cut short or stopped entirely. You are not able to take him out to the theatre, dinner or take him out socially.'
'I do not go anywhere. It is difficult to have friends round because I do not know if she will be OK, although they do know all about her.'
'I did not have people round to our home because of lack of money.'

Social events involving alcohol presented particular difficulties for the carers of alcoholics:
'I could not go out as much as I wanted to. I have had to leave weddings early because the reception was held in a pub and if we went there then she would drink. It is really difficult. People would invite you round for dinner and there would be alcohol there.'
'It is non-existent because of the embarrassment. We had lots of invites and I made excuses not to go. It was always my excuses. I did not want to go because I did not want to be shown up and embarrassed. I warned him not to show us up when we go to family things.'

One or two carers mentioned that they had lost friends:
'We have lost friends though his drinking. It is sometimes difficult to maintain friendships and socialise when he is drunk. When he is drunk he has opinions. They are offensive and his Mr Angry comes out.'

6.6.9 Effect on the carer's plans for study, at school, college or university

Approaching a third (30%) of the carers reported that the person's substance misuse had affected their studies, or plans for study, at school, college or university, see Chart 6.4.

This included university and training courses:
'When he was here full time, I was doing an OU course and failed the exam by 1% because of him. I dare not start again at present.'
'When the drug use started I was doing an OU degree. I did finish it but it took longer. I started an MA course but it got interrupted and I had to stop it. I did one of the three years. I do not know if I will start it again.'
'I was on a computer course and a testing course. I had to give them both up as she was in Addenbrooke's Hospital and I was spending so much time either there or getting there and back. When she came home I was totally exhausted and that dragged me down.'
'I had to abandon a computer course that I needed for work half way through. We did try to do a computer course together but that did not work out.'

6.6.10 Other effects of the substance misuse on the carer

The carers also reported that the person's substance misuse had affected them in other ways. These included:
'She has been violent to me. She was smashing the place up as well. The police have been involved and that is embarrassing. I was willing to press charges but they were not willing to take it further. I think that thought that because it was two girls they did not take it seriously.'
'It makes me feel responsible for his future. I feel that before I die I will have to make lots more provision for him in case he is still unable to look after himself. He is still like a child to me, but he should be an independent man. There is a feeling of great devastation and real unhappiness when you see other young people happy and well.'

6.7 The hardest thing for the carers to cope with

When the carers were asked what had been the hardest thing to cope with, the main thing they mentioned was the loss of control and worry about what would happen to the substance misuser:
'Watching her deteriorate and not knowing what is happening to her. There is a realistic possibility that she could be dead somewhere at the moment. There is a bright intelligent person in there. I do not know what she is doing.'
'Seeing him going down a wrong and dangerous road – cannabis to psychosis.'
'The hardest thing to cope with is the uncertainty. Firstly, is he going to die? Secondly, is he going to kill someone? Thirdly, the money. Then you start to wish you were dead so you did not have to think about it.'
'Watching someone destroy themselves. You are only an observer, you are powerless, you can't do anything.'

Some people specifically mentioned the worry of not knowing what to do for the best:
'The mood swings. Not knowing or understanding the 'ism'. Whether I should believe what he said when he was drunk or when he was sober. If someone had said to me

“This is an alcoholic and this is how an alcoholic behaves” I might have made different decisions. I might have been more caring if I’d realised that he was ill.’
‘The emotional side of it. We are terrified he will do something silly. We do not know how to handle it. We do not know where it will go. It does not take much to knock him off his perch, he can’t handle any kind of stress.’

One person expressed frustration of not being able to obtain help for the substance misuser when there were mental health and substance misusers problems (dual diagnosis):
‘She has to escape the circle. The system does not help as she gets frustrated with it. She is anorexic but she cannot be sectioned as they say that she has to come off the drugs first before the mental health [can be treated]. There is no service that will cater for both mental health and drug addiction. She is slipping through the net. I get frustrated and angry at the system for letting her down. Everyone can see that she is a risk to herself and others.’

Others identified a variety of other pressures:
‘I am not the priority in her life. The drug comes first.’
‘Loneliness, especially as the children live back in [another county].’
‘The stress. I now find that I can’t cope with stress in the same way that I could.’
‘The dependency that he has on us, the stigma, the expense.’
‘Seeing my wife suffer. It was very upsetting to give her [the substance misuser] money [for drugs].’
‘Keeping the normality and keeping the secrets. He has no idea of the pressure that puts on me.’
‘The family situation. You would be walking on eggshells. When someone has a problem it is there all the time. You could feel disloyal to him. You couldn’t be normal with everyone.’
‘It is very hard to take on bringing up a grandchild. It has been successful but what if it had not have been? It was immensely hard, but I saw that it benefited the child so I took heart.’
‘I don’t know, it is all just a nightmare. I think it is my loss of self esteem and confidence.’

6.8 Carers’ views on how well they had coped

When asked how well they felt they had coped with the person’s substance misuse, there was a varied response. Some thought that they had coped well:
‘I think I have done amazingly well. I have been through it. I have set the boundaries with her now and she knows the boundaries too.’
‘I think that I have dealt with it pretty well. I am pretty strong. You get a lot of abuse from them [substance misusers] even though they are family.’

Many felt that they had dealt with the situation better over time:
‘Better in the last two to three years. It was worse in the past. I went to pieces and was on medication etc. I was a nervous, gibbering wreck actually. I did contemplate ending it.’
‘Not very well. I did not feel I was coping very well at the time. I felt rock bottom and could have gone into a corner and rolled up into a ball. But, I have got through and come out at the other end. I did not give up on him or me.’
‘Once we knew that she was on a methadone programme that helped. We are not too bad now. She is feeling a lot better. My wife is feeling a lot better also.’

Sometimes this was due to support received from a self help group or partner:
'Not very well until I went to Families Anonymous. Then I started coping. I am coping better now. I am trying to get him into the habit of buying his own food and not being dependent on me for it.'
'Up until Al Anon 18 months ago I was not coping well at all. I have learnt lots of techniques now.'
'I have worked very hard on helping him. It is easier now that I have the support of my second husband.'

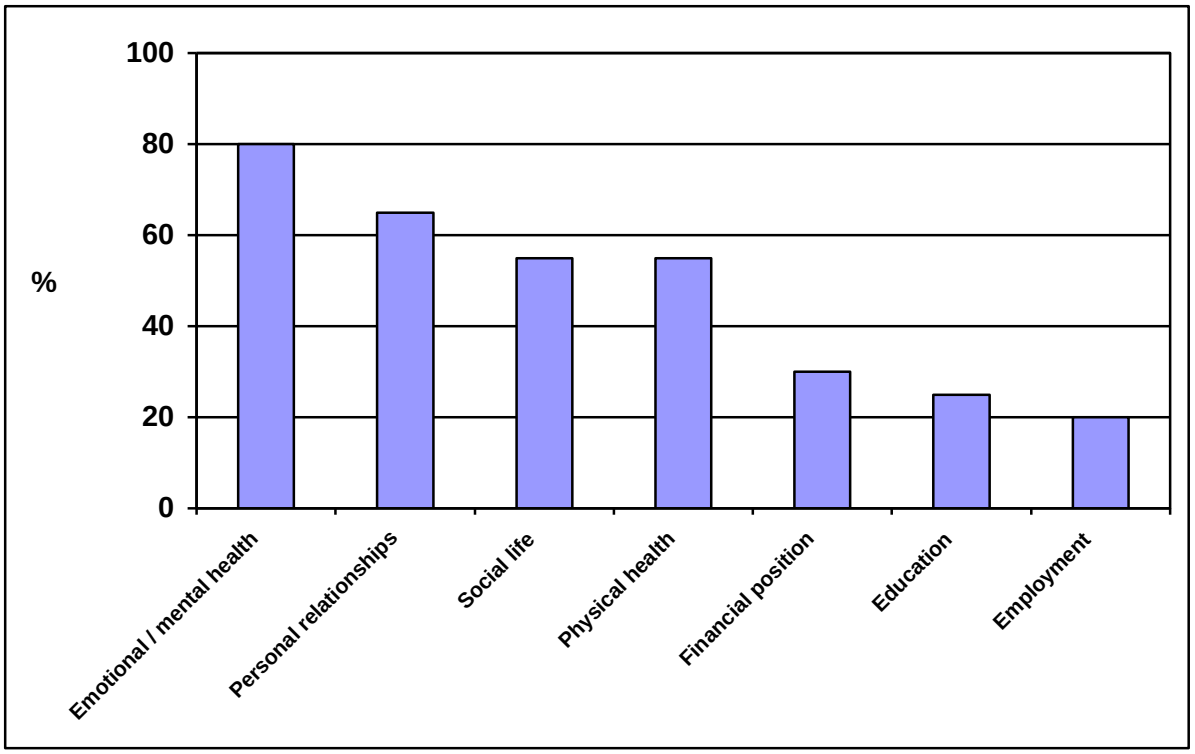
Some felt that they had not coped well at all:
'Not well at all. We did what we could. We did not know what we were up against. We did not know that drugs mask other problems and he was therefore vulnerable.'
'Not very well really, because of the anger and lack of sympathy that I feel. Even though he is using the drugs as a palliative, that is how I feel.'

Others gave a mixed response:
'My husband has coped really well, been really steady. I've coped really badly.'
'In public very well. You put on a public face. In private things are very different.'

6.9 The effect of the drug / alcohol use on other family members

The carers were asked about seven specific aspects of the life of other family members that might have been affected by the substance misuse. Chart 6.6 shows the proportion that said the person's substance misuse had affected specific aspects of the life of other family members.

Chart 6.6 Effect of the substance misuse on other family members



n=20

6.9.1 Effect on the emotional / mental health of other family members

Eighty percent of the carers reported that the person's substance misuse had affected the emotional / mental health of other family members, see Chart 6.6. Many of the carers had noticed a negative effect on the mental health of children in the family. A few mentioned the affect on their spouse / partner or parents:

'My grandson is very damaged emotionally from the early years with his mother, social services agree with me about this.'

'My daughter says that she can't deal with her emotions until her children grow up because they have to come first. She has huge wells of anger, rather like a volcano.'

'It has affected the mental health of my children. They cannot cope with anything bad or bad news. I do not think they have got over his death fully. They have anxiety attacks. One child has had counselling.'

'My partner finds it a struggle.'

'It has been terrible on both my mum and my dad. Drug users know no boundaries.'

6.9.2 Effect on personal relationships of other family members

Sixty five percent of the carers reported that the person's substance misuse had affected the personal relationships of other family members, see Chart 6.6. Again, many of the carers reported adverse effects on the substance misuser's children:

'He has a son aged 12 years. They have not lived together since he was aged one.'

'The contact between my daughter [the substance misuser] and her children is difficult. My granddaughter now sees her at birthdays and Christmas, it is upsetting for her. My daughter has decided that her children are not her real children. They have been killed and substitutes put in their place.'

Where the substance misuser was the carer's partner or spouse, they also spoke of adverse effects on their own children:

'My older daughter partly left home at age 16 years. She was very clever, she organised to go to 6th form college in Norwich, so she was away during the week, and then she would be busy at weekends. She was very angry with me.'

Other comments included:

'There have been a lot of arguments between the sisters.'

'It has been going on for so long with her family. They are despairing and fed up. They were not expecting this relationship. They were expecting to move on to a different part of their life.'

'It put a dreadful strain on the family. Each member has their own feelings and was very upset. I don't think it has caused any rows, just stress.'

6.9.3 Effect on the social life of other family members

Just over half (55%) of the carers reported that the person's substance misuse had affected the social life of other family members, see Chart 6.6. Most of the comments were on the effect on the children, rather than the wider family:

'The children will not bring friends around. The children's friends now know that he drinks. He has been abusive and racist to some our children's friends when he has been drunk.'

'The boys kept it very secret. They had few friends come round from school and they have not kept in contact with any of their school friends. One of my sons only told his university friend a few weeks ago, they have known each other for years and his friend was shocked that he had never been told.'

'The children have missed out on holidays.'

6.9.4 Effect on the physical health of other family members

Just over half (55%) of the carers reported that the person's substance misuse had affected the physical health of other family members, see Chart 6.6. Most of the comments appeared to be related to emotional / mental health problems and/or be stress related:

'My older son is asthmatic. My other son has lost weight and had stomach problems.'

'When my son got out of [psychiatric hospital] he went and broke my daughter's door down and attacked her partner, it affected her health.'

'My daughter has an eating disorder. I diagnosed it but I did not recognise it for a long time. My daughter says that she is an addictive personality and food is her drug of choice.'

'My father has been ill recently. My mother said it was due to him worrying about my son that had upset him.'

6.9.5 Effect on the financial position of other family members

Approaching a third (30%) of the carers reported that the person's substance misuse had affected the financial position of other family members, see Chart 6.6. It had effected them for a variety of reasons:

'My mother has helped us a lot financially. The two uncles paid off a loan and we then repaid them.'

'When she was in hospital the cost to get there was very high. There were all the train fares to get there. They had to borrow money to get over there.'

'Yes, because all the children went into low paid jobs.'

There were also issues about other family members lending money to the substance misuser:

'His sister has lent him money and his grandmother also lent him a little.'

'My oldest daughter helped him with some clothes. Families Anonymous and the Matthew Project talked us out of helping him financially.'

6.9.6 Effect on the studies, or plans for study, at school / college / university, of other family members.

A quarter of the carers reported that the person's substance misuse had affected the studies, or plans for study, at school / college / university, of other family members, see Chart 6.6. The carers reported how the substance misuse had effected young people's schooling in a variety of ways. A couple of carers said that the school was aware of the situation at home:

'He was not going to school and was getting into trouble, then he came to live with me and began to prosper at school.'

'Our daughter would not go to boarding school, because, in her eyes, her brother came back from boarding school a drug addict.'

'We could not afford heating in the bedrooms and the TV was always on in the sitting room, as my husband would not turn it off. They never did their homework at home, they either did it at school or not at all.'

'School has been very good because they did offer counselling.'

6.9.7 Effect on the employment, or the employment plans of other family members.

Twenty percent of the carers reported that the person's substance misuse had affected the employment, or the employment plans of other family members, see Chart 6.6.

One person suggested that the substance misuse had effected their children's career options and choices:
'My younger daughter is definitely an under achiever and a carer. She has worked in nursing homes as a carer. She did work in a factory but would not take a promotion because she would have to do some training. She has now trained to be a nurse and has been promoted within a year. I think that it is due to his alcohol that she is a carer in her work.'

6.9.8 Other effects on other family members

In addition, some carers reported that the person's substance misuse had affected other family members in other ways. This included:
'When they have seen me upset, it upsets them. My oldest child was very anti him for a while.'
'They do not want him in the house. If he comes they are angry with me.'
'It made a difference to whom the girls married. One daughter married a schizophrenic, my younger daughter married a drinker.'

Where the substance misuser had died, one carer said:
'It has affected the whole family dynamic. There is always a piece missing.'

6.9.9 Hardest thing for other family members to cope with

When the carers were asked what was the hardest thing for other family members to cope with, some carers said that it was seeing the effect on the substance misuser:
'Seeing him look so poorly. When they were younger it was harder for them to understand. He was like a father figure to my children. They were confused at what was going on.'
'Watching her suffer.'

Some carers said that it was the effect on family relationships:
'They find his behaviour, as related by me, very distressing. They consider that I should have looked after myself and not put up with what was happening. They have been supportive when it has suited them, and usually only down the phone.'
'The boys find it hard that their grandmother is not interested in them. We all just get on with our own thing. My sons are probably co-dependent too.'
'They had young children and they wanted to protect them.'

Others mentioned the behaviour arising from the substance misuse and the uncertainty about the future:
'The rudeness. The mood swings and the fluctuations.'
'The insecurity, not knowing what will be happening. The frustration of not being able to do anything about anything.'

Two carers commented on the mental illness rather than the substance misuse:
'Knowing that their brother has a severe mental illness.'
'It has caused a lot of dissension. There is discussion over whether or not she should have medication for her mental illness - I can see the benefits, my son was opposed to it. He must have minded that I did not listen to him.'

6.10 Overall, how well would you say other family members have coped with his/her drug / alcohol use?

The carers were asked how well other family members had coped with the substance misuse. Their responses were fairly evenly split between those who felt that they had coped well and those who had found it difficult to cope.

Comments on other family members, who had coped well, included:
'Not bad, pretty well on the whole. The grandchildren talk about it quite a lot. They know that he is a recovering alcoholic. It confirms to them how dangerous addictions are, a salutary lesson for them.'
'My parents, who are in their 80s, have coped very well. They have not cut him out in any way. For example, I have just booked a holiday for my husband, my son and me, and my parents have paid for my son's cost.'

Comments on other family members who had found it more difficult included:
'Actually my mum and step dad spilt up because of her behaviour.'
'Not very well, there is a lot of mixed emotion, the children love their dad but can't understand or accept some of his behaviour. They get very confused.'

The responses also revealed that, in some cases, the carer had mainly coped on their own, as either other family members had not really been involved or because the carers had shielded them from the situation:
'They coped well apart from their concern about protecting their young children. They just got on with their lives. For them it was not happening really, as they were not here and involved with what was going on.'
'We are not a close family, so it is neither here nor there to them.'
'Seeing me upset, seeing me without money and struggling. But I always got them birthday and Christmas presents. They were fine because what they did not know did not hurt them. I am good at putting on an act with the family and people I work with. I have protected them from it – I am a mum.'

6.11 Summary

- Some of the carers had been caring for the substance misuser for many years, a quarter of them for ten years or more.
- The carer was not currently living with the substance misuser in 45% of cases.
- The carers described a wide range of care and support that they provided to the substance misuser, due to their use of drugs and / or alcohol. The key activities mentioned were providing emotional support and being there to help the substance misuser.
- This included providing money and financial support, providing domestic support to those living with them (washing, cooking, cleaning), doing or helping with shopping and providing food or meals for those not living with them, making appointments and accompanying them to appointments. Other activities included: monitoring their medical needs, supervising their medication, providing housing, providing transport, taking them out and dealing with letters.
- The carers identified the main problems experienced by carers of substance misusers. They referred to the emotions they had to deal with as well as practical issues. These included stress, fear, isolation, frustration and anger, difficulties with obtaining information and support, issues related to confidentiality and financial worries.
- Half of the carers said that they saw themselves as 'a carer',
- The carers reported on how the person's substance misuse had affected their life:

- 90% or more of the carers reported that the person's substance misuse had affected their relationship with their partner, their emotional / mental health and their financial position. Based on the 'social malaise inventory' (Rutter et al., 1981), half of the carers had a 'marked' or 'high' emotional stress level.
- Over 60% of the carers reported that the person's substance misuse had affected their relationship with other family members, their physical health, their employment or employment plans and their social life.

- Over half reported that it had affected their plans or wishes for future employment and for a third it had affected their studies or plans for study.

- When the carers were asked what had been the hardest thing to cope with, the main thing they mentioned was the loss of control and worry about what would happen to the substance misuser. Other challenges included: not knowing what to do for the best and the frustration of not being able to obtain help for the substance misuser when there were both mental health and substance misuse problems.
- When asked how well they felt they had coped with the person's substance misuse, there was a varied response. Some thought that they had coped well, many felt that they had dealt with the situation better over time and some felt that they had not coped well at all.
- The carers reported on how the person's substance misuse had affected the life of other family members:
  - Over 80% of the carers reported that the person's substance misuse had affected the emotional / mental health of other family members.
  - Over 60% reported that it had affected the personal relationships and the social life of other family members.
  - Over half reported that it had affected the physical health of other family members and a third reported that it had affected the financial position of other family members.
  - Over a quarter reported that it had affected the studies, or plans for study, of other family members.
  - Over a fifth reported that it had affected the employment, or the employment plans, of other family members.
- When asked how well other family members had coped with the substance misuse, the carers' responses were fairly evenly split between those who felt that other family members had coped well and those who felt that other family members had found it difficult to cope. The responses also revealed that in some cases the carer had mainly coped on their own, as either other family members had not really been involved or because the carer had shielded them from the situation.

Section Seven
Sources of Help and Support Used by Carers

7.1 Introduction

This section looks at the sources of help and support used by carers. The carers were asked a series of general questions about whom they had contacted for help and support. They were also asked whether they had contacted seventeen different types of agencies and, if so, they were asked to rate the quality of the help provided.

This section also explores what other sources of help or support the carers knew of, what other help they would like, their advice on what carers should do and their views on how services could be improved.

7.2 Action taken by carers to find help and support

In most cases the carers answered questions about sources of help and support in respect of help for themselves, but they sometimes also included services for the substance misuser. This happened more frequently when the substance misusers had mental health problems.

All but one carer said that they had contacted someone for help and support, see Chart 7.1. In 20% of cases the carers had contacted someone within six months of starting to provide support for the substance misuser, see Chart 7.2. A quarter had contacted someone between two and ten years, but approaching a third had not contacted anyone for help and support for over ten years, in some cases much longer. Those who had not contacted anyone for over ten years tended to be carers of people with alcohol problems. How far this would be true of a larger sample is not known.

Some carers had not looked for help for a long time:
'For twelve years I coped on my own, due to pride and denial.'
'For all of them it was over 20 years.'

Chart 7.1 Carer contacted anyone for help and support

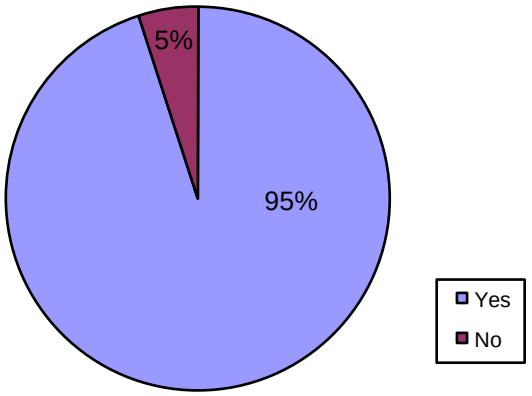
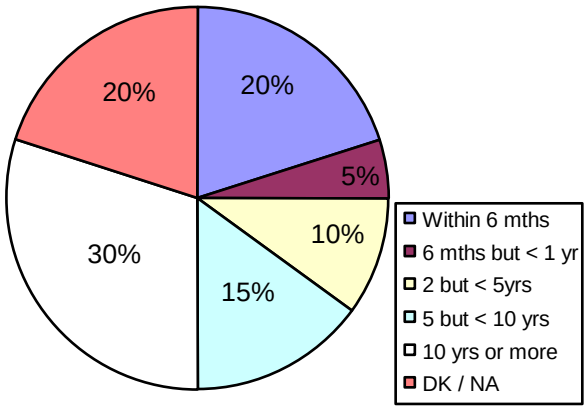
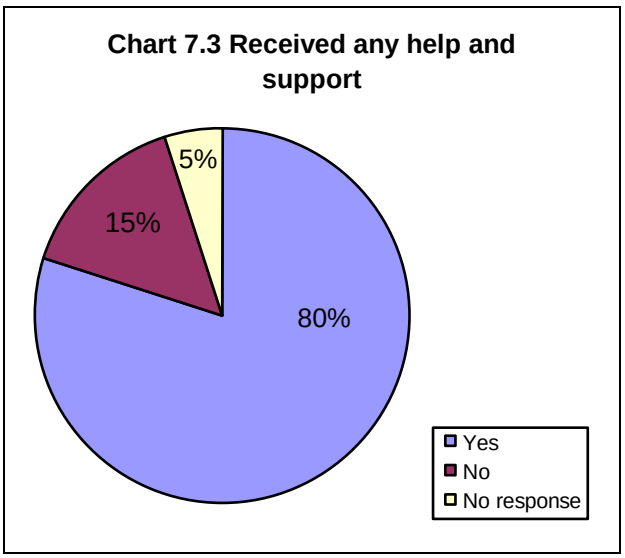


Chart 7.2 Length of time before carer contacted anyone



n = 20

Overall, 80% had received some form of help and support, see Chart 7.3.



n = 20

The responses to these initial questions about help and support provided some insights into carers', sometimes desperate, efforts to find services to help the substance misusers:
'We have been researching places for eight years now. We also get recommendations from friends.'
'We have been to the Princess Diana hospital to find out what help is available. We have been twice. It is very expensive, but we are prepared to pay. I have stayed on in my job to be able to pay for it if it comes to that.'
'I saw a programme on TV about a place called Clouds, where you can go and detox. It costs £8000 for a six week detox, I could not see social services paying that much money. We have never had a proper social worker. As she lives with me she does not get much formal help. I phoned Clouds and they sent me information. In the information I found out about Drinkline. I phoned Drinkline and they gave me the Victoria Street Alcohol Service number. It all comes under mental health, but no-one in mental health had mentioned it to me!'

One carer had made numerous appointments for the substance misuser but she had not kept them. The carer, who was well informed about the services available, concluded:
'We really need guidance. The agencies need to be more proactive and less reactive. They only come to help at the time or after a crisis.'

Although the provision of services for substance misusers is a separate issue to the provision of services for carers, the lack of support for substance misusers, or the difficulties of getting them to engage with services, increased the pressure and stress experienced by carers.

Some carers had contacted everyone they could think of, others had just contacted one or two places. Some carers had found out about agencies through the Mental Health Directory. One very well informed person, who cared for a substance misuser with mental health problems, had only recently found out about Rethink, an organisation that supports mental health carers. Many carers were not aware of any services specifically for carers of substance misusers.

The only person who mentioned Families Anonymous, a self help group for carers of drug users, had found out about them through mental health services. Her CPN had referred her to her local Mental Health Support Team, who had in turn told her about Families Anonymous.

The responses also illustrated how some of the carers had moved from being a 'hidden carer' to someone in receipt of services:
'I have been trying to stop smoking for the past year and my smoking cessation worker told me about Rethink.'
'We found out about the Matthew Project when my son was in the cells. A representative of the Matthew Project visited my son. My son rang and said that he thought we were going to get some help. A man from the Matthew Project then visited me.'
'My husband found out about Al Anon from Alcoholics Anonymous and told me to go.'

The lack of awareness of specialist services by GPs and other professionals was also highlighted:
'We wish we had known about Al Anon earlier. Our friend, who is a doctor, had never heard of it. We had never heard of it in the twenty years that we had been concerned about our son.'
'Our GP did not know about the Princess Diana hospital.'
'There is no link between the GPs and Al Anon or the Princess Diana hospital or any other treatment centre. A friend of ours in Scotland went on the internet to find out about clinics, she found one in the south of England.'

The challenges of physically accessing services was also highlighted:
'NORCAS [in Norwich] was so far away from where we live.'
'We heard about Al Anon from a friend. She gave me a number in Cambridge and I spoke to the person briefly. Cambridge seemed a long way to go for help. We then made a second effort and found out there was an Al Anon in Norwich, which was still a long way to go. We then found out there was one in a town nearer to us.'

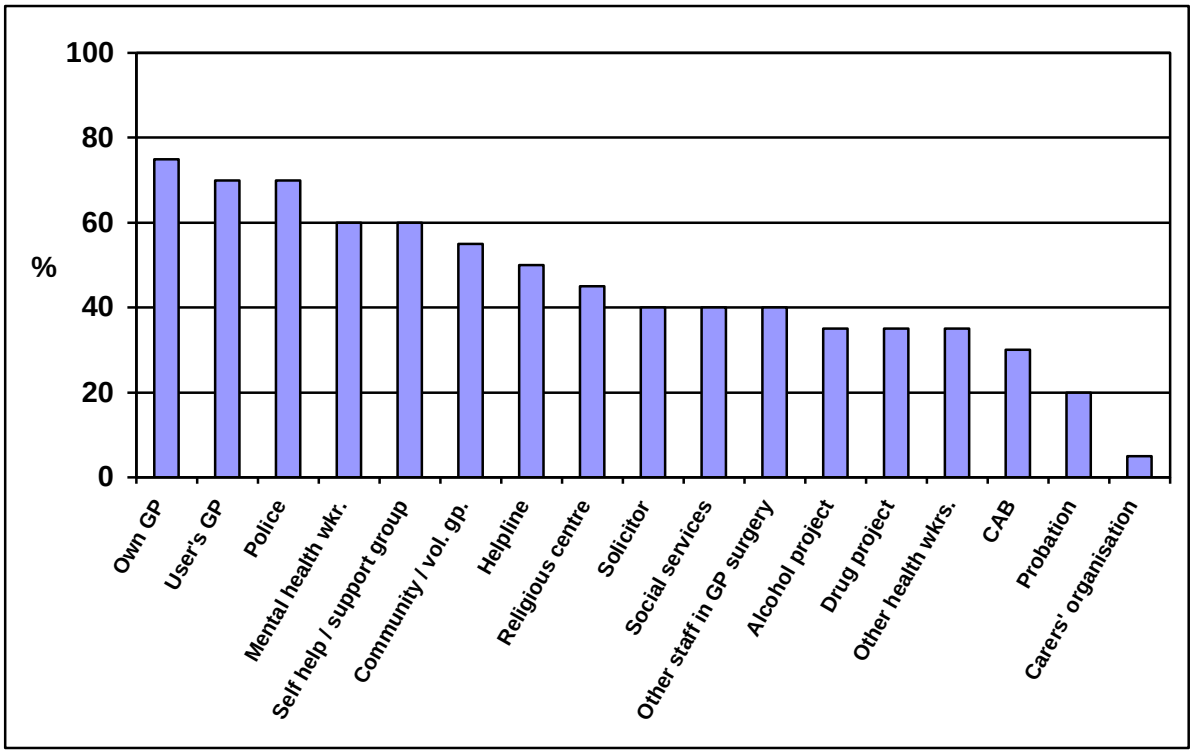
This challenge was not confined to people in rural areas. One carer, who lived in Norwich, had attended one meeting of a local Al Anon group but could not attend again due to transport difficulties:
'The Samaritans and my son told me about Al-Anon. I just went to one meeting because of the problem of getting there. I had no car and no money for a taxi.'

One of the carers pointed out that she worked in an organisation that provided support to carers. It was therefore difficult for her to make use of some of the support services available.

7.3 Specific sources of help and support

The carers were asked whether they had ever sought help and support from seventeen specific types of agencies. Their responses are shown in Chart 7.4 and are discussed in more detail below. The carers' views on the quality of the support provided is shown in Charts 7.5 to 7.20. This information on the quality of support provided should be treated as indicative, as only a few carers providing a rating for some agencies. The number is shown on each individual chart (n = number of carers).

Chart 7.4 Agencies contacted for help and support



n = 20

Charts 7.5 to 7.20 Quality of help and support provided by specific agencies

Chart 7.5 Quality of support from own GP (n=15)

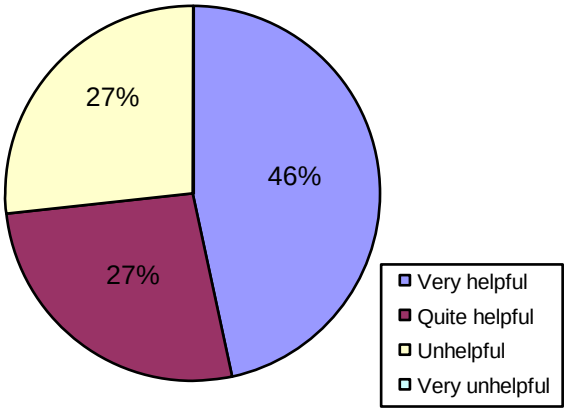


Chart 7.6 Quality of support from substance misuser's GP (n=14)

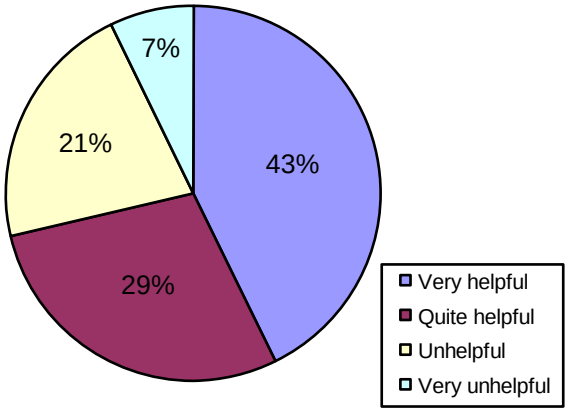


Chart 7.7 Quality of support from the police (n=13)

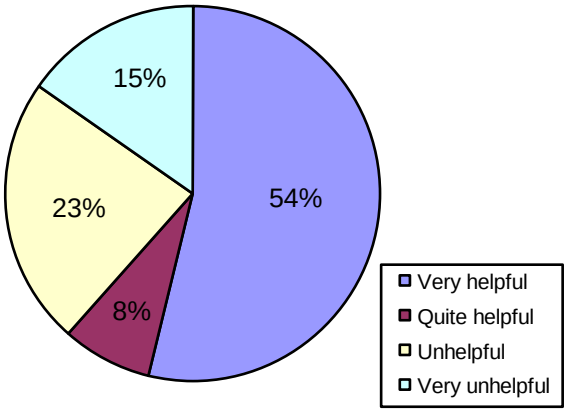


Chart 7.8 Quality of support from mental health worker (n=10)

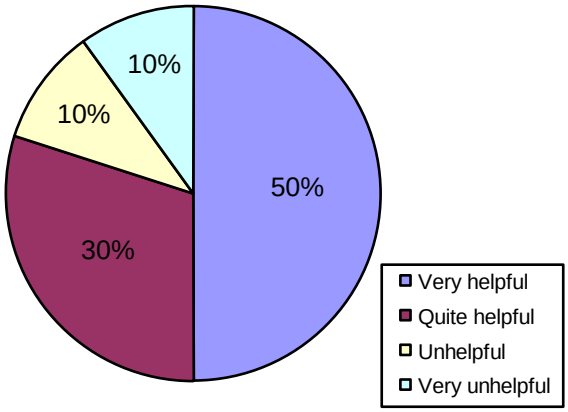


Chart 7.9 Quality of support from self help / support group (n=12)

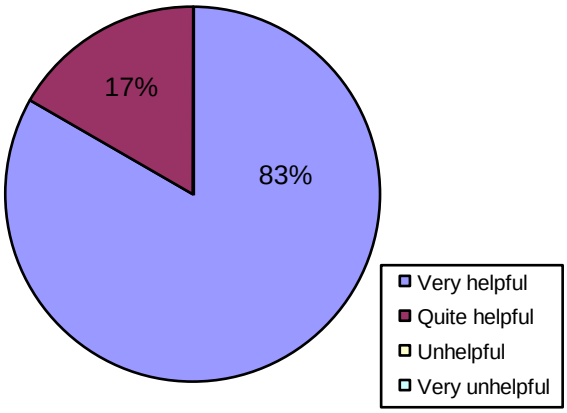


Chart 7.10 Quality of support from community / voluntary oganisation (n=11)

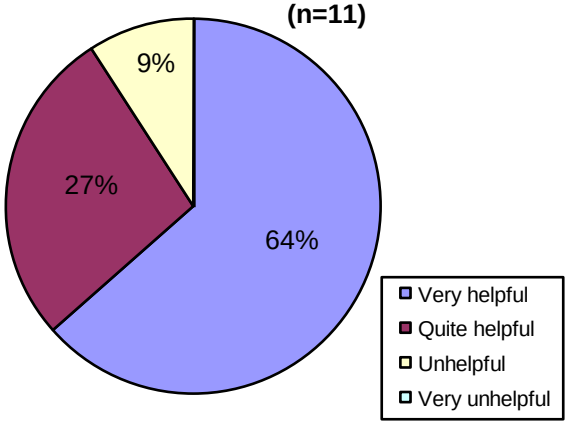


Chart 7.11 Quality of support from telephone helpline (n=10)

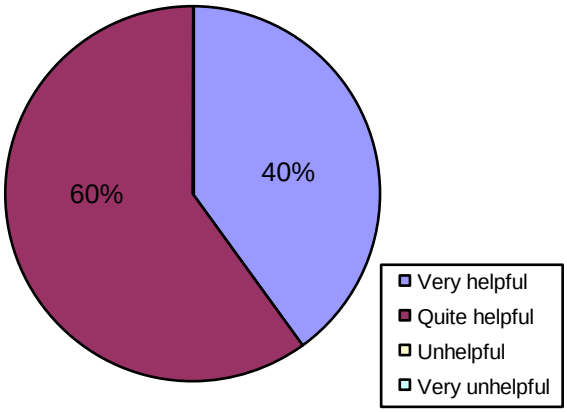


Chart 7.12 Quality of support from religious centre (n=9)

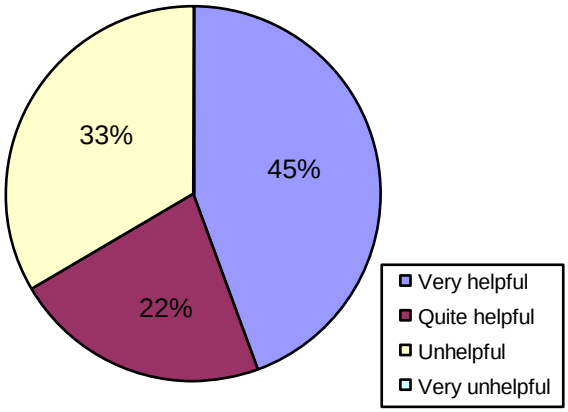


Chart 7.13 Quality of support from solicitor (n=8)

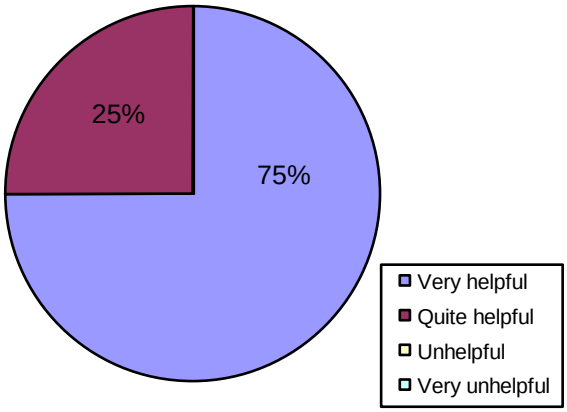


Chart 7.14 Quality of support from social services (n=8)

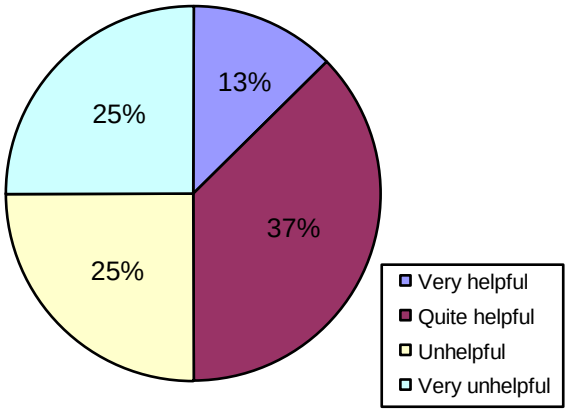


Chart 7.15 Quality of support from other staff at GP surgery (n=7)

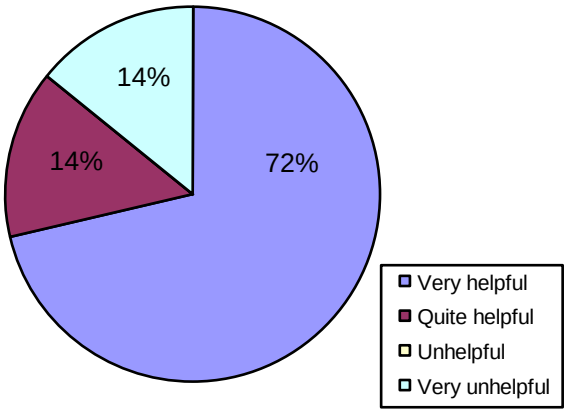


Chart 7.16 Quality of suport from alcohol project (n=7)

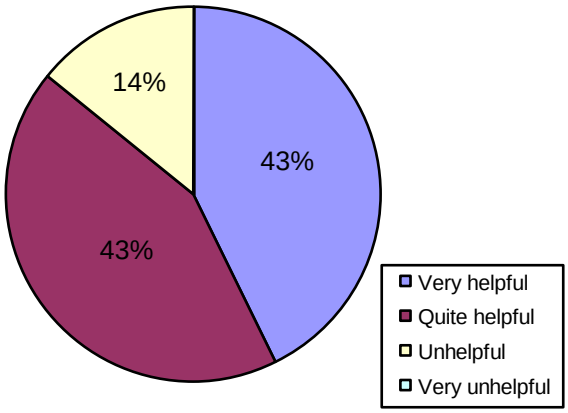


Chart 7.17 Quality of support from drug project (n=6)

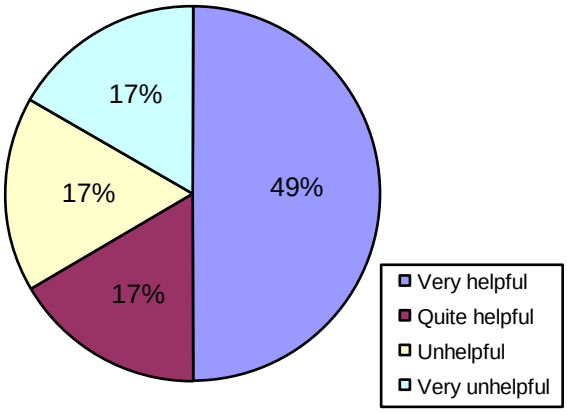
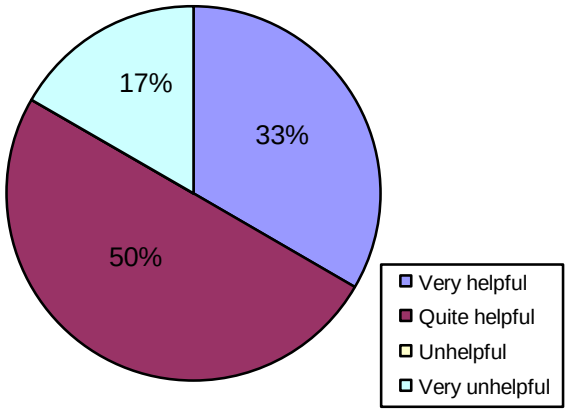
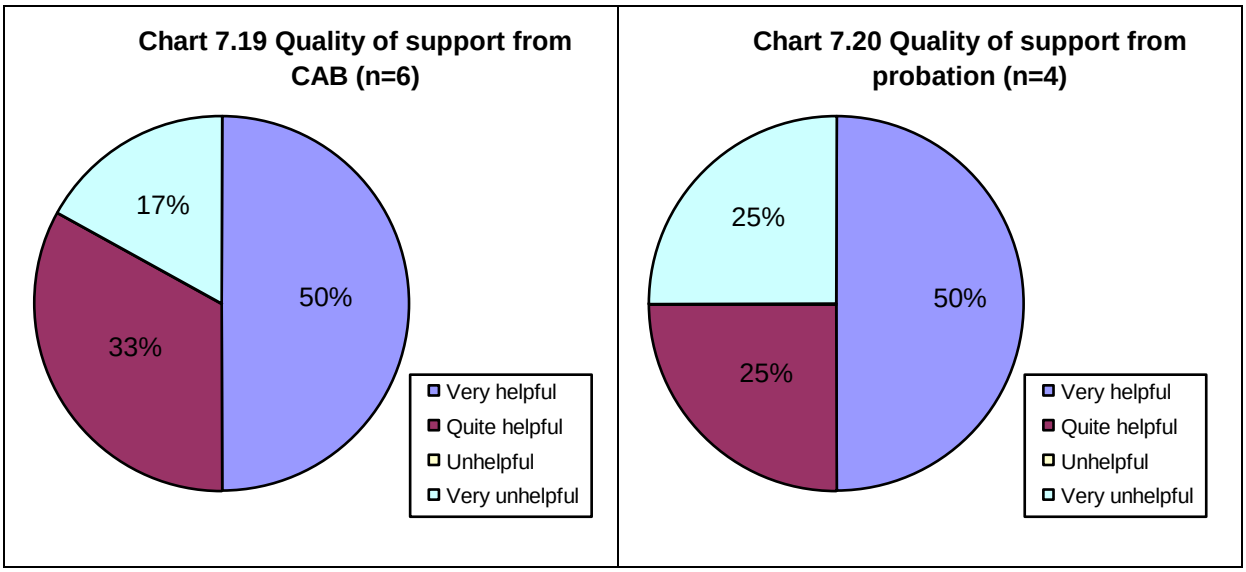


Chart 7.18 Quality of support from other health workers (n=6)





7.4.1 Contact with the carer's GP for help and support

The most mentioned source of help and support was the carers' own GP, 75% of the carers had contacted their own GP, see Chart 7.4. Out of the 75%, 46% felt that their GP had been 'very helpful'. However, 27% felt that their GP was 'unhelpful'. see Chart 7.5. The main types of support that GPs had provided were medication for stress and emotional / mental health challenges, listening, referral for counselling, referral for other services and information.

Some people commented on the helpful attitude of their GP:
'The first GP helped me with my emotional state. He gave me tranquillisers and let me sit and talk to him, he told me to leave my husband. The second GP, she is lovely and she always makes time for me. I went for my depression, I am still on tranquillisers and she is still helpful.'
'He has tried to fill the gap now that I do not have a CPN.'

Some felt that their GP had not really helped them:
'You see different GPs, it is rarely the same one twice. I have spoken to the GP in a general way. I have not really been offered anything, I do not want to take pills.'
'I feel as if I am sidelined. I am just a caring role. I am merged and blurred together with the person whom I care for. The emphasis is on the other person. You need your own appointments.'

Others said that they had had mixed experiences:
'We had a supportive GP, he was lovely. When he left the amount of support went down. The present GP has said: "If you don't watch it you will become unemployable" and he has told me to "ditch the alcoholic". I think that he is very unprofessional.'

GPs were also seen as a route to obtaining others services, although one person expressed frustration that the GP had not been able to achieve more in this respect:
'My GP wrote to social services when I wanted help for [the substance misuser]. They did not even reply.'

None of the carers recalled their GP talking to them about being on a carers' register or joining a carers group. However, two carers reported that someone else had talked to them about joining a carers group. One carer said:
'I have noticed that they are doing a register at the surgery.'

Others commented:
‘He would if she had a physical disability. ‘
‘He didn’t see me as a carer.’

7.4.2 Contact with substance misuser’s GP for help and support

The second most mentioned source of help and support was the substance misuser’s GP, 70% of carers had contacted the substance misuser’s GP, see Chart 7.4. In most cases this was to obtain help for the person they were caring for rather than themselves. Out of the 70%, 43% felt that the substance misuser’s GP had been ‘very helpful’, however 30% felt that the substance misuser’s GP had been either ‘unhelpful’ or ‘very unhelpful’, see Chart 7.6.

Some carers had experienced reluctance by the substance misuser to see their GP:
‘He has been depressed for a long time and is on anti-depressants. I tried to get him to the GP earlier, but he would not have it.’
‘Before my son went into hospital I realised that he was not well so I went to see his GP. The GP was helpful, he said that my son must go and see him himself, but he would not do so, so the GP was not much use.’

In some cases the GP was reported as providing more help with the mental health problems than the substance misuse problems:
‘My daughter’s GP is a locum and knows about mental health and has worked with my daughter’s psychiatrist. My daughter can see her GP anytime. She can speak with him and discuss her medication. I can go with her too.’
‘Very helpful, but there was nothing the GP could do but pass him onto the Mental Health Trust. I have never really spoken to the GP about the drugs and alcohol, just the mental health problems.’

The difficulty of getting treatment in cases of dual diagnosis was again commented on:
‘I went with my son to see his GP. The GP referred him to the CPN. The GP, CPN and my son then met without me. The GP could not do anything about my son having to be off drugs before he could have a mental health assessment. If he could have done this, this would have been very helpful.’

In cases where mental health was not a particular issue, GPs were often seen as not being able to provide much help for the substance misuse:
‘He understood there was a problem, but he could not do anything about my husband.’
‘He knows the situation. He can’t do much, but he is aware.’

Some carers commented on issues of patient confidentiality:
‘He was an adult patient and therefore there is patient confidentiality. I can accept that. But as a parent we wanted to know what would help and what would hinder his situation.’

In some cases the substance misuser had been taken off the GP register:
‘Our GP sacked him because of his attitude.’
‘We did have the same GP for a while but he struck her off.’

A few carers had received some help for themselves through the substance misuser's GP:
'I asked for help on his behalf. Help was offered I took up some counselling. He saw a specialist for his alcohol. They did talk to me.'

7.4.3 Contact with the police for help and support

The police were also seen as an important source of help and support, 70% of carers had contacted the police for some form of help and support, see Chart 7.4. Of these, over half (54%) felt that the police had been 'very helpful'. However, 38% felt that the police had been 'unhelpful' or 'very unhelpful' see Chart 7.7.

When the carer was worried that the substance misuser had gone missing, the police were usually seen as helpful:
'On two occasions I rang the police because I could not contact my husband because he was not at the phone box as arranged. The police went to the house at 2 a.m. to check he was there.'
'Once when she had been drinking and went missing and I knew that something was wrong. She phoned me and I phoned the police, who put out a bulletin to find her. They found her and took her to hospital, she had taken 80 Ibuprofen [pain killers]. The police stayed with me.'
'The police get a thumbs up. The first three times he went binge drinking, I had him registered as a missing person and they gave him a talk after he re-appeared.'

Some people had called in the police due to offences committed by the substance misuser. They had mixed views about how helpful the police had been. Some felt that the police had been helpful:
'I contacted the police many years ago, right at the beginning. On my request they came and searched his room for drugs. The police were lovely, excellent, very helpful.'
'After they came round that time they rang and emailed to check that we were OK. I think that the situation frightened all of us.'
'They also offered me support as a victim.'

Some were less positive:
'I contacted the police because my husband was physically and emotionally abusive because he was drunk, and I was frightened. The police were more helpful in [another county] than in Norfolk. In [another county] they took him away for the night. In Norfolk they just left him with me. It was not safe, so I got out of the house and slept in the car.'

One carer pointed out that the substance misuser was wary of the police:
'The police were not helpful. He was afraid of them. Like a lot of drug users he would not mention that he was using heroin as they would use that to put pressure on him to get information.'

7.4.4 Contact with a mental health worker for help and support

Overall, 60% of carers had contacted a mental health worker for help and support, see Chart 7.4. Out of the 60%, half felt that the mental health worker had been 'very helpful', and a further 30% felt that mental health worker had been 'quite helpful', see Chart 7.8. In most cases the contact was in relation to the substance misuser's mental health, not their own.

Even some of the carers who thought the mental health support was 'very helpful', were not entirely satisfied with the support provided for the substance misuser's mental health.

Some were not happy with the support provided in the hospital setting:
'We have had contact with the mental health Access Team when we first had all the trouble, they were not very good. We had to apply through the GP and three weeks later they still had not come.'
'I saw her when she was in [psychiatric hospital]. It is terrible. They need more trained staff with compassion to the patients and the families. If you go in there voluntarily you then start doing cold turkey. She gets violent when this happens so she is then kicked out. What is going on!'

Some identified the need for more community based support:
'I'm very dissatisfied and I am thinking of making a formal complaint about the inadequate care in the community. The mental health workers consider drugs and alcohol to not be their problem. They do not even know what the different drugs are. I am not happy with the consultant, the CPN or the social worker. I go to my son's CPA reviews but they are a waste of time – nothing has been done about his use of drugs and alcohol. They only treat his mental health problem. They should organise treatment for his drug and alcohol use.'
'The psychiatrist is very helpful. He specialises in manic depression and is very good. He gives good support but she has no other mental health support. We would like more mental health support, we have wanted a CPN for three years.'
'I asked for help when she was in hospital. She was sent home with no support. I got very stressed from that. I couldn't cope myself. I was passed from one person to another. There were no crisis numbers six months ago. So after a few days she was suicidal and back in [psychiatric hospital].'

Four people had had contact with a mental health worker for their own health. One person received mental health support services in the community and found them very helpful. The other three people had had support from mental health workers in the past. They had mostly valued this support, but not always. One of them still wanted some mental health support:
'I have seen a CPN and a psychiatrist for my own health. The first CPN was brilliant. The second CPN did me a lot of harm. He talked about himself and did not face my issues of feeling agoraphobic and wobbly and frightened.'
'Very helpful – I had a CPN until last summer, the CPN has now been taken away. I would still like CPN support.'

Some of the carers indicated that they welcomed the respite provided when the substance misuser was sectioned:
'If that happened [being sectioned] we could all have a little more sleep at night knowing that she was safe and secure and not having a choice about coming off drugs.'

7.4.5 Contact with a self help or support group for help and support

Overall, 60% of carers had contacted a self help or support group for help and support, see Chart 7.4. Out of the 60%, 83% felt that the self help or support group had been 'very helpful', and the remainder felt that self help or support group had been 'quite helpful', see Chart 7.9.

Five carers mentioned Al Anon, an organisation that has local support groups for carers of people with alcohol problems. Two of the five carers had been contacted for interview through local Al Anon groups. Those who belonged to an Al Anon group found it very helpful,
'Al Anon is a lifeline. We look forward to it every week. You can unburden yourself or hear others unburdening themselves.'
'I have joined Al Anon they have taught me coping mechanisms. They have been a great success for me.'

Most of those using Al-Anon stressed that participation in an Al-Anon group involves looking at your own behaviour, and some pointed out that it was not appropriate for everyone:
'I am learning not to let the situation affect me. Al Anon is hard. It is living in the now. It is all about putting yourself first. It works and it is self supporting. Prior to Al Anon I kept asking why he was doing it to me and the children. I felt inadequate and that it was my fault.'
'You have to want it and be prepared to do the work. Two ladies came to the group who were sent by their GP, but it was not appropriate for them.'

Four carers mentioned Rethink, an organisation that supports carers of people with mental health problems. These four people had been contacted for interview through Rethink, none of the other carers mentioned it:
'I heard about Rethink through a person in a similar situation to me. The March conference was the first meeting that I had been to. I thought that they were lovely people. I will be going back. It is by going to things like that that you hear about organisations.'
'Rethink are very supportive and very helpful. They are always willing to listen.'

One carer belonged to Families Anonymous, an organisation that has local support groups for carers of people with drug problems:
'Families Anonymous have helped me to stay strong and be tough on my son.'

One carer mentioned the Manic Depressive Fellowship, a mental health self help group:
'We found out about the Manic Depressive Fellowship on the internet. I contacted them and joined my daughter up for £5 a year. ….. I can go to the Manic Depressive Fellowship with my daughter. I might go with her next time she goes. I do not know of anywhere else'.

Some carers were very clear that this type of support was not appropriate for them:
'I am aware that there are places where I can talk to others in my situation. It is not what I need, it is not what my son needs. I have enough problems with him, I do not need to sit and listen to other people's problems. I do not want to do it, I feel that it is all patronising.'

7.4.6 Contact with a community or voluntary project for help and support

55% of carers had contacted a community or voluntary project for help and support, see Chart 7.4. Out of the 55%, 64% felt that the community or voluntary project had been 'very helpful', and 27% felt that community or voluntary project had been 'quite helpful', see Chart 7.10.

Three carers had received support from community projects funded by the NELM (North Earlham, Larkman and Marlpit) Development Trust in Norwich. These projects are supported by New Deal funding and cover three estates in Norwich.
'The NELM Community Support Workers. They were fantastic. They were very professional and very good. They diffused the situation correctly. My respect for them has increased greatly as a result of seeing them in action.'
'I contacted my friend who contacted the community wardens to come and collect the used needles. They were mainly in the house and some in the bushes in the passage. It is embarrassing, so I talked to my friend and went through her.'

Two carers had received support from the Linking Together project in West Norfolk. These two people had been contacted for interview through the project:
'The Linking Together worker has made calls on my son's behalf, visited him and gone to appointments with him. She has been a saint.'
'She has mostly provided support and talked things over things with me. She spoke to me on the phone when I got in a state. I think Linking Together is wonderful and it is vital that the support is there. There is no one else, that I could find, that could help me in the same way.'

Two carers mentioned Mind, a mental health charity,:
'Mind helped me with some self support. I saw their carers leaflet and saw that they do counselling for carers.'

Other community or voluntary projects contacted by the carer included:
- Focus, a specialist substance misuse counselling service in Bury St Edmunds
- St Martins Housing Association
- The Family Rights Group
- The Grandparents Federation
- The Salvation Army.

One carer had also contacted Bridges, a mental health drop in centre, and the Norwich Community Workshop for services for the substance misuser.

7.4.7 Contact with a telephone helpline for help and support
50% of carers had contacted a telephone helpline for help and support, see Chart 7.4. Out of the 50%, 40% felt that the telephone helpline had been 'very helpful', and the remainder felt that it had been 'quite helpful', see Chart 7.11.

Three carers mentioned the Samaritans:
'I rang the Samaritans on those desperate nights, when you just pick up the phone to hear a reassuring voice.'

One of them had found out about Al Anon from the Samaritans.

Two carers had rung the Carers Helpline, run by Crossroads – Caring for Carers. Another carer had recently obtained the number for the Carers Helpline but had not yet rung them. One of the carers, who had contacted the Carers Helpline, felt that they were unhelpful as their subsequent application for support from another agency had been turned down.

Other helplines or telephone contacts, each mentioned by one carer, were:

- The UK National Drugs Helpline (now 'Frank')
- Alcoholics Anonymous
- Drinkline
- The Matthew Project Helpline
- Al Anon
- NHS Direct
- The psychiatric hospital help line (this is probably a reference to the Crisis Resolution Home Treatment Team, who give out a number to people whom they are in contact with, they were formerly called the Access Team)
- The prison help line – the NACRO Resettlement Plus Helpline
- A debt helpline.

In some cases the contact with a helpline was to obtain help for the substance misuser rather than the carer.

7.4.8 Contact with a church or religious centre for help and support

45% of carers had contacted a church or religious centre for help and support, see Chart 7.4. Out of the 45%, 45% felt that the church or religious centre had been 'very helpful', 22% felt that the church or religious centre had been 'quite helpful' and a third felt it had been 'unhelpful', see Chart 7.12.

Some carers had received considerable support:
'I go to church. My son is on the prayer list. The vicar has provided a lot of support. Also the prison chaplain went to see my son.'
'I saw the local rector because I did not know what to do. I was looking for support. I saw a Christian counsellor.'
'I was really surprised they were great. They were a great help especially prior to his death, and at the time of his death the priest and nuns were very good.'

Others were not so positive:
'I went to the local vicar once. He was unhelpful; otherwise I would have continued the contact. Over the years you give up expecting much help.'
'My son is Jewish. I was concerned that my son was not getting prayers etc when he was in [a psychiatric] hospital. I contacted the hospital chaplain, but did not find him helpful. The churches do not help people as much as they should.'

One person pointed out:
'The priest did all the right things, but I did not appreciate it at all. If I had gone to Al Anon first then I might have understood what the priest was on about.'

Some wanted to keep their spiritual life separate from the substance misuse issues:
'We go to church but we do not talk about it in church. It is not something we have wanted to talk about.'
'I already had a spiritual group. I did not go and get help from them specifically as I have Al Anon for that support, I need to keep other aspects and interests in my life unaffected by the alcoholic.'

7.4.9 Contact with a solicitor for help and support

40% of carers had contacted a solicitor for help and support, see Chart 7.4. Out of the 40%, three quarters felt that the solicitor had been 'very helpful', and the remainder felt that the solicitor had been 'quite helpful', see Chart 7.13.

Solicitors had been contacted for a range of reasons including: legal representation of the substance misuser in court, issues related to the care of the substance misuser's children, substance misuser's mental health rights, financial and property matters and possible divorce proceedings. Comments included:
'Many times. Once when my son was sectioned and he wanted to appeal. Again when my son was having problems with his benefits and university loan, they were excellent.'
'I did ring a solicitor because I wanted to know what I had to do if I needed to do a moonlight flit. I was making contingency plans. I got some very good advice with regards to the property.'
'To discuss possibly divorcing my husband, it was a threat to stop him drinking.'

7.4.10 Contact with social services or a social worker for help and support
40% of carers had contacted social services or a social worker for help and support, see Chart 7.4. Out of the 40%, half felt that social services had been 'very helpful' or 'quite helpful', see Chart 7.14. Some people pointed out that it was not them but the substance misuser or the substance misuser's child who had a social worker.

Some of the carer's more positive views of social services were:
'I have a mental health social worker [for my mental health problems]. She is not allowed to help much in relation to my son but she did provide me with some information to help with his housing problems.'
'We had a social worker phone us when I first wanted her diagnosed for her mental health problems. The social worker got us an appointment with the psychiatrist and came with us to the appointment. She said that my daughter did not need a social worker because she lived with me. She may get more help when she has her own place. The social worker did get us the mental health diagnosis.'
'Yes, but I did not have a social worker. My granddaughter's daughter had a social worker. They came to my house and had meetings. They asked if I would be there as my granddaughter was aggressive.'

Others had less positive experiences:
'I had contact over the situation with the grandchildren. I was registered as my grandson's foster mother therefore I felt that I should receive some support. They said I should ask for support as my daughter's carer!'
'I have had contact with social workers as part of my son's mental health problems. They are absolutely hopeless. I've had to do it all myself for my son – organising housing benefits etc.'

7.4.11 Contact with other workers at a GP surgery for help and support
40% of carers had contacted other workers at a GP surgery for help and support, see Chart 7.4. Out of the 40%, over three quarters (86%) felt that other workers at a GP surgery had been 'very helpful' or 'quite helpful', see Chart 7.15.

The main other workers mentioned were practice nurses and counsellors. Most people had found them helpful:
'I saw the nurse. There was a big blow up where he was smashing the place up. I had a bad asthma attack where my breathing was out of control. I have been given some breathing exercises to help control that. She suggested that I then go to the GP and put him in the picture.'
'The Practice Nurse has been very good to me. I can go and see her whenever I want.'
'The counsellor helped me to cope.'

Some people had had less positive experiences of obtaining counselling through their GP:
'We did ask to see a counsellor but it was about the same time as Soham. They were all giving help down there and were busy.'
'I was offered some counselling and when I went the counsellor started crying.'

A couple of carers had encountered difficulties with other staff:
'Once my son had gone into psychiatric hospital, I went to the surgery to get some support, as I was near to desperation. The receptionist said that they had no information. So I said "There are no mental health problems in [town] then?" All I wanted was some information and support and someone to listen. She was very superior.'
'The key worker did not get back to me when emails were sent. They tend to be relieved that he is not in contact with them.'

In response to this question, two carers also mentioned Contact NR5, a community substance misuse treatment service based in a GP practice in the NELM area of Norwich.

7.4.12 Contact with an alcohol project or alcohol workers for help and support
A third of carers (35%) had contacted an alcohol project or alcohol workers for help and support, see Chart 7.4. All but one carer thought that they were 'quite helpful or 'very helpful', see Chart 7.16.

Four of the carers had had contact with the Victoria Street Alcohol Service (now part of the Alcohol and Drug Service, Norfolk and Waveney Mental Health Partnership NHS Trust). In all cases this had been for the substance misuser. One carer was not happy with the service offered:
'The Victoria Street Alcohol Service was not very good. She went to the Victoria Street Alcohol Service, before we knew about her manic depression. But they would not detox her unless she had been clear for a week, by which time she would not really need a detox!'

Another carer, who had some professional knowledge of substance misuse services, said:
'The Victoria Street Alcohol Services are great. They work on care plans. They should be involved with DTTOs [Drug Treatment and Testing Orders] as alcohol is a real big problem for too many people.'

Three of the carers had had contact with NORCAS in respect of alcohol problems only. This had been both for themselves and for the substance misuser:
'The NORCAS counsellor was amazing. She will be pleased at how much I have moved on from when I was seeing her. However NORCAS promote "controlled drinking" and I do not agree with this, as, in my husband's case, it is the first drink that leads to the chaos.'
'My daughter gets counselling and I get counselling too, which is very helpful. She also gets acupuncture and goes to the drop in on Wednesday mornings. When we mentioned NORCAS to the psychiatrist, he said stick with them, they are the best.'

Two of the carers had had contact with Contact NR5. This had been primarily for the substance misuser. One of the carers would have liked some support for themselves:
'He was with Contact NR5, before and after his detox. I know the main worker to say hello to but I have not had an appointment or sat and talked to her. I do not feel the

need to anymore, I would have loved to a while ago. I see my GP now, she always makes time for me.'

One of the carers had had contact with the Matthew Project in respect of alcohol problems only. They had obtained support for themselves:
'The Matthew Project was recommended to me by a neighbour. I paid for counselling there, they were lovely.'

The Diana Princess of Wales Treatment Centre (commonly referred to as the Princess Diana hospital) was mentioned by one carer:
'We have had good meetings with the Princess Diana hospital – the issue was whether or not our son is an alcoholic. We thought that the Princess Diana hospital would have given us some help – such as information on places to go.'

7.4.13 Contact with a drug project or drug workers for help and support
A third of carers (35%) had contacted a drug project or drug workers for help and support, see Chart 7.4. Half of them thought that they were 'very helpful', see Chart 7.17.

Four carers mentioned the Matthew Project in relation to drug misuse and drug and alcohol misuse. This had been both for themselves and for the substance misuser:
'The Matthew Project counsellor was very helpful. She was the only help that we really had.'
'A man from the Matthew Project Counselling Support Team visited me and said that I needed to put up some boundaries. I had counselling from the Matthew Project for two years.'
'The Matthew Project Housing Team found my son accommodation in Norwich just before he went into prison the first time. He had to give it up because he was in prison. They found out for me that he had been sentenced to prison.'

Two carers mentioned NORCAS in relation to drug misuse and drug and alcohol misuse. This had been both for themselves and for the substance misuser:
'We had a letter from NORCAS to refer us to a self help group when we couldn't take it any more.'
'My son went to NORCAS, but then he went into prison so did not get offered much. He was offered acupuncture, which he refused as he does not like needles, despite injecting himself with drugs. He never really got underway with NORCAS.'

Two carers mentioned Contact NR5:
'I have not contacted Contact NR5 myself because they are there for the drug user. They can't contact me unless the drug user agrees.'

One carer had contacted CADS (Community Alcohol and Drug Service) to get help for themselves:
'We have been to CADS two or three times just asking for information. They are already helping my son. They look a bit nonplussed, but they have always helped us. For example, I found a packet of white powder in my son's flat and I wanted to know what it was.'

A couple of carers had had less positive experiences of drug treatment agencies:
'We have had to push drug workers to see him. We were told he would have an assessment after two days. Ten weeks later he still hadn't been seen.'

One carer had contacted the Diana Princess of Wales Treatment Centre to obtain services for the substance misuser.

Overall, 55% of the carers had contacted a drug and / or alcohol agency.

7.4.14 Contact with other health workers for help and support
A third of carers (35%) had contacted other health workers for help and support, see Chart 7.4. Most of them thought that they were 'quite helpful', see Chart 7.18.

The main other health workers mentioned were staff in hospital Accident and Emergency Departments (A&E). The carers were generally happy with the service provided, but some commented on the lack of follow up:
'When my husband had been binge drinking I took him to the A&E at the hospital. After keeping him for some hours they just said to take him home.'
'I have been to A&E hundreds of times, when she has cut herself or overdosed. Nothing happens, they usually just stitch her up and send her home. Last time she had an overdose, they kept her in overnight to sleep it off and she had to see a CPN before she left. The contact with the CPN led to her appointment with the psychiatrist being brought forward. They are helpful when she is there but there is no follow up. They just patch her up and send her home.'

One carer had experienced problems in obtaining services for the substance misuser, who lived on the Norfolk Suffolk border:
'We fall in the gap between Norfolk and Suffolk. For the NHS he is under the West Suffolk Hospital. His social services department is Norfolk.'

7.4.15 Contact with the CAB (Citizens' Advice Bureau) for help and support
Approaching a third of carers (30%) had contacted the CAB (Citizens' Advice Bureau) for help and support, see Chart 7.4. Most of them thought that they were 'very helpful', see Chart 7.19. The CAB had been contacted for a variety of reasons, both on behalf of the substance misuser and for the carer themselves. Topics discussed included: advice on finances and debt, housing advice about a pending eviction of the substance misuser, information on caravan sites and help with GPs.

7.4.16 Contact with Probation for help and support
A fifth of carers (20%) had contacted Probation for help and support, see Chart 7.4. Most of them thought that they were 'very helpful', see Chart 7.20. Some of the carers indicated that they would have liked more contact with Probation concerning the substance misuser.

7.4.17 Contact with a carers' organisation for help and support
Only one of the carers had contacted a carers' organisation for help and support, see Chart 7.4. One person commented that they had not contacted a carers' agency as they thought that they were only for older people.

7.4.18 Contact with someone else for help and support
The carers had also contacted other people and agencies for help and support. These included:

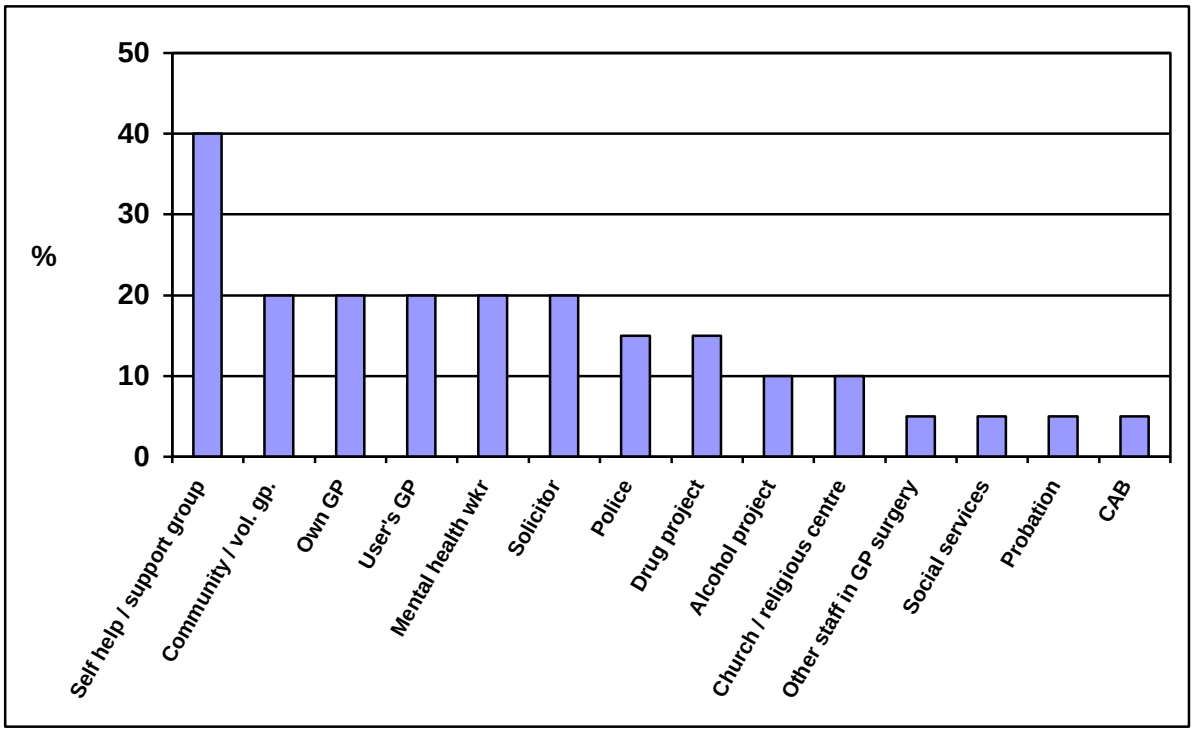
- A friend who was a psychiatrist
- A psychiatrist in South Africa
- The carer's boss
- The national office of Rethink
- The mental health advocacy service

- The district council, who had helped with re-housing the carer
- Re-Solv, who were contacted via the internet. They provide information and support related to solvent and volatile substance abuse.
- A hotel receptionist, who had to let down the substance misuser's car tyres so that he could not drive the car whilst drunk
- Other family members and friends.

7.4.19 The most helpful agencies

The carers were asked to identify up to three of the agencies that had been the most helpful to them, see Chart 7.21.

Chart 7.21 Most useful or helpful agency overall



n = 20

Self help or support groups were in the top three for 40% of carers. The groups mentioned included Al Anon and Families Anonymous.

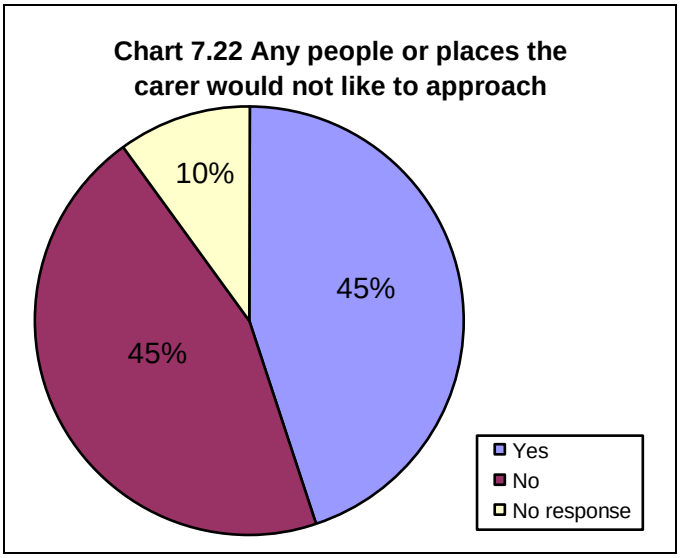
Their own GP, the substance misuser's GP, a mental health worker, a community or voluntary project and a solicitor were in the top three for a fifth of carers. The community or voluntary projects mentioned included: Linking Together, Rethink and the Grandparents Association.

The Police and a drug project / drug workers were in the top three for 15% of carers. An alcohol project / alcohol workers and a church or religious centre were in the top three for 10% of carers.

One carer could not identify any agency as being the most useful or helpful:
'None of them. None of them network and talk to each other. Most of them will have had contact with her except Crossroads because she is the wrong age group. The rest, they are pants'

One carer stressed:
'We have not had help for our son, because everyone says that he has to help himself. We want help with him, not for ourselves.'

7.5 People or places that carers would <u>not</u> really want to go to for help
When asked if there were any people or places that they personally would <u>not</u> really want to go to for help, 45% of carers said that there were, see Chart 7.22.



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Three carers, who dealing with dual diagnosis issues, said that they would not really want to approach psychiatric services:
'Our son is excluded from treatment. Psychiatrists have sacked him in the past.'
'Psychiatrists – I find them very unhelpful.'

Three carers identified specific drug and alcohol treatment services they would not want to go to for support:
'NORCAS because they are not helpful to alcoholics. They give you something to try that simply does not work, they are an example of what not to do.'
'The Bure does not accommodate the needs of the clients.'
'CADS because they are a health initiative. It seems that if it is a health initiative it gets money because the NHS is seen as better.'

A couple of carers said that they would not really want to go to social services:
'The social workers I have come across have been hopeless – ineffectual, slow and judgemental.'

Other sources of support that carers would not really want to approach were the police, housing, their GP, the GP's receptionist and self help groups:
'My GP. The ethos of the service is good, the practicality is poor though.'
'Doctors' receptionists. They are not all awful, but the majority seem to be.'
'I do not want to go to these self help groups where there are people who have someone in the family with a problem.'

A couple of carers commented:
'We will try anything.'

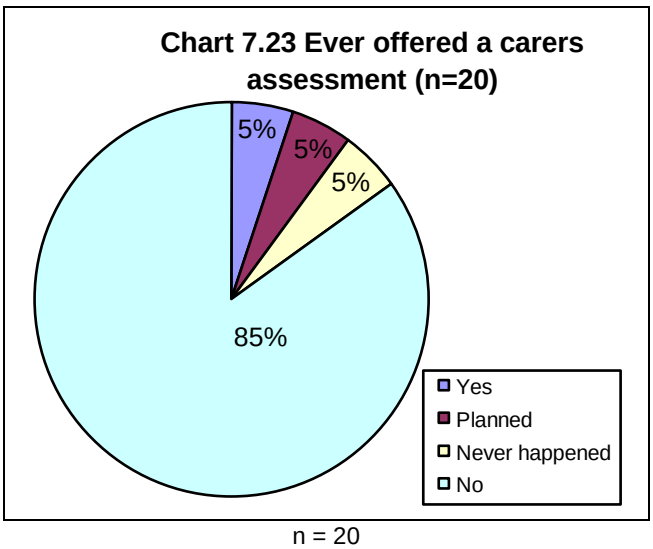
Two carers spoke about why they had not approached agencies in general for help:
'Basically I have not been to others because it is family and you just feel … at the end of the day it is your family and even though they are in your house doing these things you can't discuss family matters with just anyone.'
'Drugs bring on shame to the families and this is at all walks of life. I do not feel comfortable with everyone knowing my situation. But when the drug addict contacts an agency they could contact the families and say that there is support out there if it is needed.'

7.6 Carers' assessments

Three carers had been offered a carers assessment, see Chart 7.23. Out of these, one had been offered an assessment but it had never happened and another was planned. The person who had had an assessment explained how it had come about:
'I had an assessment for being a carer because of my own mental health issues. I got my own social worker. I didn't realise that I could get this. I thought that it was for old people.'

However, the carer had not been impressed by the outcome:
'Not a lot comes out of the assessment, you feel let down, there is nothing concrete or tangible. I have heard of a couple of groups. The assessment is there for a reason. There should be something come out of it, not just another review.'

Some were not sure how they would benefit from a carers' assessment:
'I don't need it now myself. I'm not sure if I would have understood in the past. It is difficult to know what they could have offered except someone to talk to who understands, like the people at Al Anon.'
'I do not need money, I can't see what help they can give me. But I am assured that it will be a good idea.'



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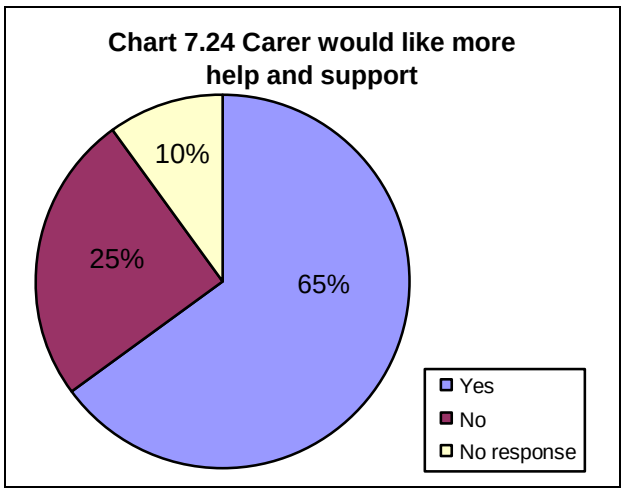
7.7 Other help or support wanted

The carers were asked whether they would like any other help or support. Approaching two thirds (65%) said that they would, see Chart 7.24.



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Some carers wanted more information about the support available or provided to the substance misuser, some wanted more help for the substance misuser. This was particularly true for those with mental health as well as substance misuse problems:
'The confidentiality issue is the big one for us.'
'Getting information about what is happening with his mental illness. Mental health carers are not given information or told what to ask for or what is available out there.'
'I would like my son to be diagnosed with mental health problems and receive some treatment.'
'I feel, but I am ashamed to say it, that people should be sectioned to protect them from themselves and others.'

Some wanted more information on how to handle the substance misuser:
'We would like to know how to handle the situation. Al Anon advise us on how to look after ourselves. We want to know how to help our son. We have had no help with that. They say he has to realise his problem for himself.'

Some wanted more support for themselves:
'I would just like my CPN back, but you don't do miracles do you? The CPN was taken away because I was better.'
'I would have liked to know about the carers helpline. Social services department is 9 – 5 whilst the helpline is 24/7.'
'It would be nice to have a voice at the end of the phone if you feel wobbly. I can be open [in the support group], but sometimes I put on a bit of a front at the meetings. It would be nice to speak to someone anonymously. Sometimes, even now, I want to run away and escape it all.'

Three people, who did not wish for any more help, said:
'No, not now because it has all stopped and because I spoke to the GP and my friend. I only confided in one friend, because it is family and you don't want everyone knowing your business.'
'No, we just kept in the family. People calling her a druggie will not help. They take it out on other people. There are a lot of people round here who like to gossip.'
'No, I think that I have got over the worst. Now I want to do something to help others.'

7.8 Carers' suggestions to improve the help and support available

The substance misuse carers were asked how the help and support for carers could be improved. In many cases the carers' suggestions for improvements in support services for carers were closely linked to improvements in support services for the substance misuser. The main need identified was for information:

'You need more information on addiction. You need to know what to expect. You need to know what are the signs and symptoms.'

'Information, you do not get enough information. All we ever wanted was someone to come round and check what we needed and tell us what is on offer. You have to find out for yourself, it is a hit and miss affair.'

'A video would be good to explain things. You can then see it and can take it away with you. Leaflets would be good too.'

'We do not know because, if he were well, there would be no problem for us. The doctors could be more forthright about what it involves. It is all clothed in secrecy.'

The carers also identified the need for more communication and action by agencies:

'Agencies should talk more to you. They do not treat you as part of the team.'

'There is no communication between all the different places, for both me and for [the substance misuser].'

'I suppose that social services or mental health could do more for carers, there could be more meetings for carers.'

A number of carers wanted more recognition of the important role of substance misuse carers and their involvement in treatment plans for substance misusers:

'Carers are behind closed doors and not thought about.'

'Carers are not recognised by the professionals and the law. Some professionals hide behind the law. In mental health, the carers must be an integral part of the user's care plan.'

'I don't get help because she lives with me. They just think "Oh, her mum can look after her". I get the impression that they think that I am a really pushy mum and just interfering. However, my daughter does not think that I'm interfering. She said that she would not be alive if it were not for me.'

'There is one vital thing – carers have to be involved in every step of the user's care and treatment. In life, carers are the only ones who really care. It is not a professional thing, it is a love thing.'

One person stressed the need for more local self help support groups:

'By having more local groups, which are easily accessible to where people live. It is surprising how many people there are in my situation. Even sitting down with a cup of tea and talking helps, even if they cry all the time. You can't tell the family things, because they will not forget. I used to think that it was my fault and that I was worthless. But it's not my bloody fault, because it is him that drinks, and I suffer.'

One person mentioned the need to lift the shame associated with substance misuse:

'If alcoholism was not such a taboo subject, if it was recognised as an illness and people were not ashamed to talk about it.'

The need for more support for young people was also mentioned:

'There is not enough for youngsters. Children of alcoholics needs support. There is not enough response, there is the stigma to overcome. The only support comes from the young carers project. What about those who are not carers? Al-Anon is used more for adults. Al-Ateen needs to be developed more.'

7.9 Carers' views on the most important things that carers should know about

When asked what were the most important things that carers should know about, information was again emphasised:
'How the drugs work.'
'There are places to go to for help and support. You are not isolated and on your own. It is knowing where the first port of call is.'
'People need to know what is out there should they wish to go. More leaflets through the door or billboards.'

The value of self help support groups and the concept of tough love were mentioned, especially by those with direct experience of this:
'Tough love. There is a lot of help and support out there, but it is knowing how to access it. Meeting with other carers of drug and alcohol users.'
'Alcoholism is an illness, and a family illness. As drinkers get more sick so do we. You then having to unlearn your behaviour. You have to see that your strategies are not helpful to you or the drinker.'
'They need to know where the support groups are, where the support is so that they do not put themselves at risk. You do not think that anyone else is going through what you are going through.'

Again the carer's concern to obtain services for the substance misuser was included in their response:
'How your relative is coping – what help and support they will get.'
'What help there is for an alcoholic? We need information, but a lot of the information contradicts itself. It would be best to get information from the GP – get a leaflet which is well signed, that has a list of people you could go to for help and advice.'
'Benefits, patients' rights, medical knowledge about drugs, information on illicit drugs. I do not know a lot about illicit drugs even now. Parents are not educated to look for the signs. What is out there to help the person you are caring for, what is available.'

7.10 Carers' recommendations on what other carers should do

When asked what they would recommend that other carers should do, they first and foremost recommended that carers found some support. This could be from any source that was available:
'They access some help and support. Start anywhere just keep going. Go to your GP and the helplines and see what you have. It could be friends or support to turn to for yourself. You need someone independent who is for you. Get in touch with a group to get some help.'
'Pick up the phone, you can't do it on your own. You think you can but you can't.'
'Get in touch with Al-Anon. No matter how far they have to go to find a meeting it is worth it. You are able to talk freely. That is so much better. It is all about you. It is a chance for you to get out of the madness of the drinking.'

The stigma of alcoholism was mentioned again, along with the suggestion for help at an earlier stage:
'Although it is an illness, it is seen as self inflicted, this is part of the sorrow. As it is frowned on people hide it in drawers, it should be treated more openly. It is so hidden, it is all so secret. Children drink at school and carry on at university and this leads into alcoholism. Maybe they could help people at an earlier stage.'

Again the advice was intertwined with obtaining services for substance misusers:
'Get in touch with your GP. Reduce the money that you are giving them. You then help them the best way that you can and wean them off the drugs.'

‘Be very insistent that the problem is addressed medically. Do not let it ride for years and years. It is very difficult if the person does not want to deal with it. You have to muster up everything that is available. In the end, if nothing succeeds, you have to take a step back and let the user take responsibility for their actions.’
‘Find out as much as you can. Be as supportive as you possibly can. The [support worker] said that I was doing as much as I could, and, if it did not work, I should look after myself.’

A couple of carers had advice on keeping stress levels down:
‘Remain objective and not get too emotional about it.’
‘Make a cup of tea and put Radio Two on softly, it helped me get through yesterday when my son had a crisis and was taken to a secure unit. Just relax and live for the moment. Get your thoughts organised.’

One person just said:
‘Stay strong.’

7.11 Summary

- All but one carer said that they had contacted someone for help and support.
- In 20% of cases the carers had contacted someone within six months of starting to provide support to the substance misuser, a quarter had contacted someone between two and ten years. Approaching a third had not contacted anyone for help and support for over ten years, in some cases much longer.
- Overall, 80% had received some form of help and support.
- The carers were asked whether they had ever sought help and support from seventeen specific types of agencies. The key agencies contacted were their own GP, the substance misuser’s GP and the police.
- None of the carers reported that a GP had talked to them about being on a carers’ register or joining a carers group.
- At least half had contacted a mental health worker (either for themselves or the substance misuser), a self help / support group, an alcohol or drug project, a community or voluntary project or a telephone helpline.
- Other sources of help and support were: a church or religious centre, a solicitor, social services or a social worker, other workers at a GP surgery, other health workers, the CAB and probation.
- None of the carers had contacted a carers’ organisation for help and support.
- When asked to identify up to three of the agencies that had been the most helpful to them, 40% of the carers identified a self help / support group.
- A fifth of the carers identified their own GP, the substance misuser’s GP, a mental health worker, a community or voluntary project or a solicitor.
- 45% of the carers identified some people or places that they personally would not really want to go to for help.
- Three of the carers had been offered a carers’ assessment, but only one had actually had one.
- 65% of the carers said that they would like more help and support.
- The carers’ suggestions to improve support to carers included more information about the substance misuse and treatment, information about sources of support for themselves and more support services.
- In many cases, the carers viewed the provision of support to the substance misusers as a key source of help to themselves.

Profiles of two adult carers
These profiles are based on people interviewed for the research. The names and some details have been changed to protect the identities of the individuals.

Adult carers profile 1 – Paula

Paula and her husband have been together for over forty years, she is now in her sixties and he is in his seventies. For many years, she did not realise that he was an alcoholic. She just thought that he drank a lot.

In terms of care, Paula provided things over and above what a normal wife would provide. He just worked and she did everything else, including being in charge of spending the money. Due to her husband's drinking, they often did not have enough money for essentials, but the main impact on her was emotional:
'I coped by pretending that I did not have any feelings. We screamed at each other every night for many years, which affected the children. So I decided to stop and do whatever he said, this led to me becoming hugely resentful. I was always trying to defend my actions, it did not occur to me that I did not have to.'

They also moved house often, so Paula did not have the opportunity to make friends with people. At the time, she did not realise how desperate she was for company. Everyone knew about her husband's drinking, so she did not have to hide it, but she was very ashamed about it.

Paula reported that her husband's drinking had also affected her physical health, her relationship with her children, her social life and her employment. She had planned to stay at home to look after the children, but in the end took a part time job as she enjoyed being out of the house. However she kept forgetting when she was meant to be at work: 'I was not living on the planet at all, I had shut down all my responses.'

She felt that her husband's drinking had also adversely affected the children in a number of ways, especially their emotional / mental health. Also, when they were growing up they were not able to do any homework at home, they did not usually bring school friends home and they stopped going to discos because their dad would be drunk when he came to pick them up.

For over twenty years, Paula did not receive any sustained help about her situation. She contacted the police and the CAB once. She eventually spoke to the priest at her church and her husband's GP, but did not obtain any sustained support from either of them. Then in the 1990s, her husband, realising that he had a problem, went to Alcoholics Anonymous. He then told Paula that she must go to an Al-Anon Family Group. She has not looked back since. Although her husband has been in recovery for many years, she still attends Al-Anon as she has found that there are many issues to be dealt with now that she is living with a sober man:
'I do not know what it would have been like without him drinking. When he sobered up it was like being married for the first time, it was very peculiar.'

Adult carers profile 2 – Dorothy

Dorothy is in her seventies and has never stopped caring for her daughter, who is now in her forties. Her daughter started smoking cannabis at boarding school and then moved on to other drugs at college. More recently, she has started using cocaine. She started having mental health problems in her teens and was diagnosed with schizophrenia in her early twenties. Dorothy is not sure which came first, the substance misuse or the mental illness.

Her daughter is sometimes violent and has knocked Dorothy down when she refused to give her money. She has also threatened other people. She has been admitted to psychiatric hospital over thirty times. Before her daughter's most recent admission to hospital, Dorothy kept an eye on her, visited her frequently, shopped for her and paid for things for her. However, her main caring role has been with her grandchildren.

After her daughter's first admission to hospital, Dorothy took steps to make her first granddaughter a Ward of Court and then brought her up herself. The second granddaughter was fostered and then adopted. Some years later, Dorothy also took over the care of her grandson. This was when he was approaching adolescence as he was not going to school and was beginning to get into trouble.

Dorothy reported that her daughter's substance misuse and mental illness, and the subsequent care of her grandchildren, had affected all aspects of her life. It had affected her physical and emotional health, her relationship with her other children and her social life. She had had to give up her part time university course and reduce the hours that she worked. This, together with court cases about the care of the grandchildren, had greatly affected her financial position. In reflecting on the situation she said:
'It was a catastrophic situation for a family – drugs and mental illness combined – it was difficult to keep things together. I think that I have done as well as could be hoped for.'

Over the years Dorothy has contacted a wide range of agencies, often seeking help for her daughter or grandchildren rather than herself. This included her own and her daughter's GP, social services, mental health workers, the police, the CAB, solicitors, her local vicar, the Family Rights Group, the Grandparents Association, Mind and Rethink.

With some agencies, if the individual she approached was not willing to support her Dorothy found another person who would:
'The original solicitor left and the new one advised me not to take on my grandson. He said "You should let social services care for your grandson or else you will go to an early grave." So I went to see a different solicitor who helped me, and I am still alive!'

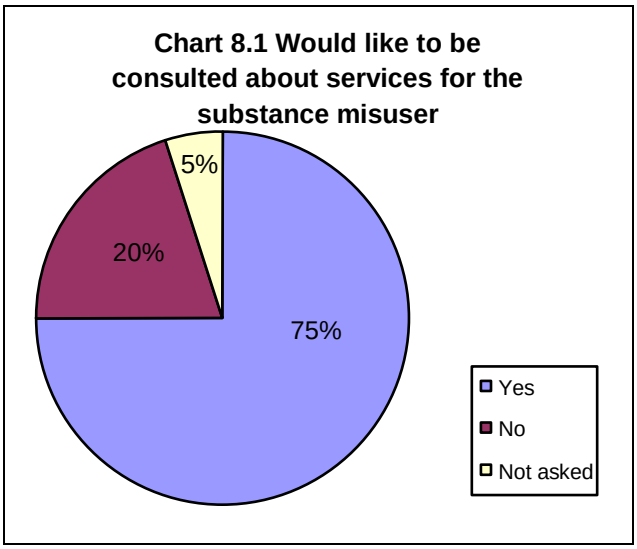
Section Eight
Consultation and Involvement

8.1 Introduction

The interviews with carers included a few exploratory questions on their views on consultation and involvement. This section presents the findings.

8.2 Consultation and involvement in the services provided for the substance misuser they cared for

Seventy five percent of the carers said that they would like to be consulted or involved in the services provided for the substance misuser they cared for, see Chart 8.1.



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There was an interesting divergence of views about the appropriateness of being involved. Some carers were keen to be involved in the services provided to the substance misuser:

'We would like to get an update on how she is getting on.'

'Yes, then I would know what is going on, and he would then have help at home as well.'

'I would like to know what is going on. I would like to know what is my place. In other walks of life we are encouraged to support what is going on e.g. at school. You do not want to do more harm than good. You may not be aware of the triggers, because you are so close you may not realise what they are. We should be working together and so I need to know what else is going on. I need to be consulted on how I can help.'

'Definitely. I would like to know about his medication and treatment. I would like to make suggestions.'

'I should be an equal partner with the psychologist, social worker and CPN at the CP reviews.'

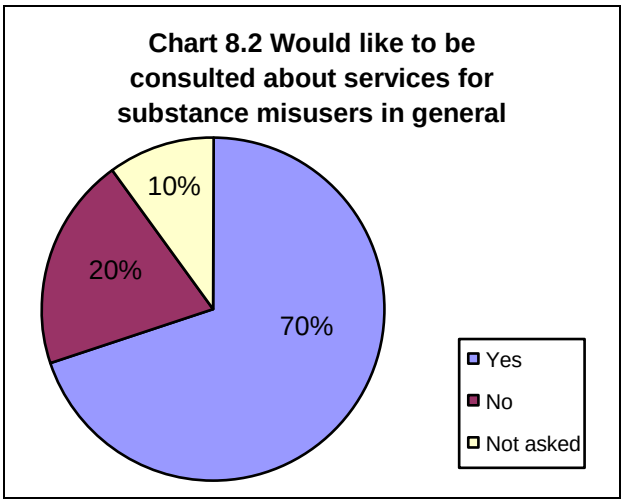
'I think that people like my son should be made to go for help. They could send the appointment card to me as well as him so that I can go and support him. I would sit in on the appointment if he wanted me to, otherwise I would just sit outside for him.'

Others were not so keen on being involved and queried the appropriateness of being involved:
'No, once they have gone for help, they get it and either accept it or not. You can't help it if people do not want to accept it.'
'I would be interested, but probably my son would not want it. I've answered questions and filled out forms for him for 20 years but now he says he must do things himself.'
'No, as he does not really go for any help. Men do not go to the doctors. It would be OK to go to the GP with him, if he would go to his GP. However his recovery is not my business.'

One carer seemed in two minds about being involved:
'Before going to Al-Anon I would have liked to have been "hands on" – although this is not the right way to go about it, Al-Anon says look after yourselves not the drinker. The drinkers can see they have a problem. Whilst we cover it up it enables them to drink. It is important that the family is involved because it is a family illness. Some drying out places do involve the families too.'

One carer was already as involved as they wished to be:
'No, I am quite involved when she goes to see her psychiatrist or GP.'

8.3 Consultation and involvement in the services provided for the substance misusers in general
Seventy percent of the carers said that they would like to be consulted or involved in the services provided for substance misusers in general, see Chart 8.2.



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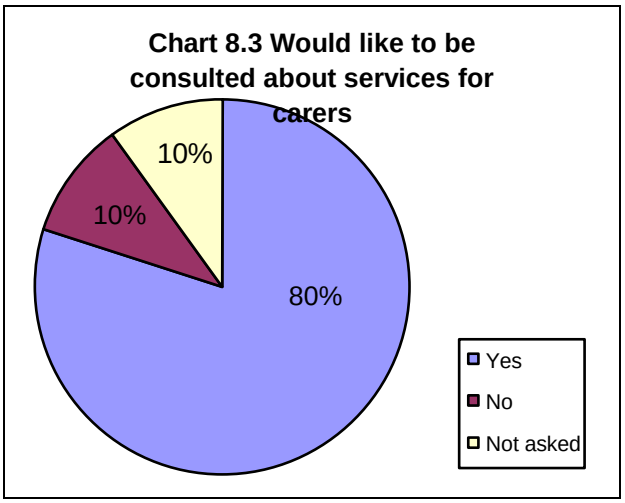
Those who were interested in being involved made a number of comments. These were mainly about what they thought they could offer and on what basis:
'I would not mind giving the benefit of my experience, or any advice that I could give.'
'I would not mind helping on a voluntary basis. I was a schoolteacher, I am used to dealing with young people.'
'Yes – newsletter and leaflets. With meetings we might have a bit of time and location difficulty. A meeting is not likely to be local. We could get to meetings [in our area], but not to meetings in Norwich.'
'A qualified yes in that it would depend on the time available.'
'I would go to meetings as a first step. I do not have a car, but it is only an hour on the bus, so it is no big deal.'

Amongst those who did not wish to be involved, some felt that it was not their business to be involved and in some cases the substance misuse was no longer a problem:
'No, it is his business, I need to keep the focus on me.'
'No, I hope it does not come my way again.'

One carer commented:
'I can't see what I would do. Would people like CADS see it as an intrusion?'

8.4 Consultation and involvement in the services provided for substance misuse carers

Eighty percent of the carers said that they would like to be consulted or involved in the services provided for substance misuse carers, see Chart 8.3.



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Those who were interested in being involved made a number of comments. Again, these were mainly about what they thought they could offer and on what basis. However, most did not know how to go about it:
'I had it bad for so many years, anything that I could pass on would be good. I did not know whom to contact or where to go.'
'I am not sure if I am up to it, but yes I would. I am concerned about what I could cope with, probably discussion and sharing experience. The only thing I could do would be to listen to other parents. One to one contact would interest me the most.'
'Consultation re carers in general – I would go to meetings as a first step. I do not have a car, but it is only an hour on the bus, so it is no big deal. Consultation re services to me – it would be one way of finding out what there is. I am not sure how to do it as I do not know.'
'A qualified yes in that it would depend on the time available.'
'Yes. But I can't see what help could be provided, but then we thought that with Al-Anon and they have helped. I don't want to see another layer of people put in place who do not fulfil the need.'
'Very happy too, but I would not really want to go to carers' meetings.'

Some carers were already involved in consultations with carers through mechanisms for consulting with mental health carers and one person commented:
'A colossal amount of people have drugs and alcohol and mental health problems.'

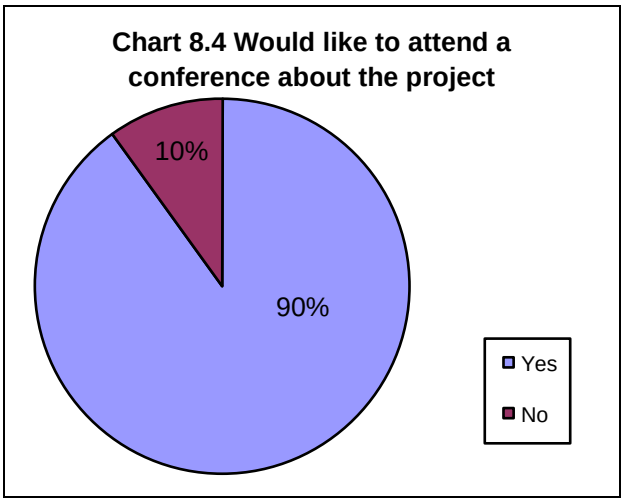
A couple of the carers were already involved with putting other substance misuse carers in contact with self help / support agencies.

Three carers made some general comments in relation to all the consultation questions:
'Yes, because it is a very scary place. However there is a problem of commitment as I am losing 6 or 7 days a month at the moment because of my health.'
'Going to groups. I would not mind giving the benefit of my experience, or any advice that I could give.'
'I would like to be involved in any way that would be considered useful.'

8.5 Attendance at a follow up conference
When asked whether they would be interested in attending a day conference, later in the year, about the results of the research and what might happen next, 90% of the carers said that they would like to be invited, see Chart 8.4.

One carer said that she could not attend, due to because of health problems, but would like some information sent to her.

Another carer was not at all interested in attending. She was the only carer who had not been very keen on being interviewed. At the end of the interview she said:
'I am very angry that I have got to do this interview, but if it will help, I feel it is a duty.'



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8.6 Summary
- 75% of the carers said that they would like to be consulted or involved in the services provided for the substance misuser they cared for.
- 70% of the carers said that they would like to be consulted or involved in the services provided for substance misusers in general.
- Some carers commented that they were very keen to be involved, whilst others queried the appropriateness of involvement with services for substance misusers.
- 80% of the carers said that they would like to be consulted or involved in the services provided for substance misuse carers.
- 90% of the carers said that they wanted to be invited to the conference following this research.

Section Nine
Young Carers

9.1 Introduction

This section presents the information from the email survey of Young Carers Projects and information relating to young carers provided by the other agencies surveyed. It also explores the situation of young carers from their own perspective based on interviews and a focus group with young carers themselves. This information is augmented by seven profiles of young carers provided by agencies working with them, some additional information on young carers in Norfolk from some research undertaken by Research Plus+ in 2004 (Research Plus+, not yet published) and some information provided for a young carers event in 2004.

9.2 Response to the young carer agency questionnaires

As part of the research, email questionnaires were sent to the agencies that work with young carers. This provided information on the services that are provided for young carers, who provide care for someone with a substance misuse problem. It also provided the opportunity to explore the views of those who work with young carers. Following telephone calls to young carers workers to check if they worked with or were aware of the needs of young carers of substance misusers, 19 questionnaires were sent out. A total of eleven responses were received. This was a response rate of 58%.

Some of the front line staff did not know whether or not the young carers they worked with were substance misuse young carers. They said that referrals would come to them as a physical or a mental health carer's referral:
'Even health and social care professionals sometimes omit the mention of substance misuse on the referral and only mention mental health problems.'

9.2.1 Services provided to young carers

There are 25 young carers groups across Norfolk. They are run by staff employed by NYCS, Norwich and District Carers Forum, Crossroads, NCH and CONNECTS & Co. with some staff running two or more groups.

From the responses by the agencies, some said that they worked with young substance misuse carers as part of their general young caring work. Agencies said that the young carers of substance misusers were entitled to the same services as any other young carer. The main focus of their work was to give them a break from caring. The young carer workers said that they would ensure that talking, if required, and signposting to services was available:
'Yes. One to one support, individual outings, working with these young carers within a group setting.'

The responses suggested that the workers often only worked with one or two young carers who were substance misuse carers at any one time.

9.2.2 Protocols followed by agencies

All agencies who apply for a Carers Grant have to work to agreed standards. The agencies were asked what 'national or local standards or protocols' they followed in their work with young carers. Most of the agencies said that it was not applicable and some said that they did not work to any protocols with young carers. In further discussions, it was suggested that these responses could be due to agencies using

different terminology to that used in the questionnaire. Three of the eleven responses provided some information related to this.

Only one response referred directly to the ACPC Protocols with another response referring to County Hall Children's services:
'All the Project staff have had training delivered by DAAT. Staff follow our organisation procedures, policies and guidance when working with children, including child protection policies and ACPC.'

9.2.3 Funding and research

When asked about funding, the Carers Grant was an important source of funding for the young carer groups. Other sources of funding were the Norfolk Children's Fund and the NYCS. Only one agency was aware of any local or national research or reports on the needs of young carers of substance misusers.

9.2.4 Issues for young carers

When asked to describe the main issues faced by young carers a number of issues were identified. The main ones identified were a chaotic lifestyle at home, the extra responsibilities and secrecy:
'Having to keep it secret. Chaotic life style. Worry about parents.'
'In the past I have found that young carers who are older can be angry and worried especially if there are younger siblings within the family that they feel responsible for. I have had situations where the young carer has lost his/her respect for the parent and in many ways has taken over the parenting role. This can include responsibility for handling the family finances, paying bills etc.'
'Their lives are very chaotic with high levels of deprivation compared to other situations. Young carers are often very angry and feeling let down. School attendance can be a problem too. They find it difficult to trust anyone and find it difficult to keep appointments. Often they are on the CP register or assessed by SSD and if not they need to be referred by us.'

It was pointed out that:
'It is very difficult to talk about substance misuse issues. The young carers are less open and find it very embarrassing.'
'Some young carers do not realise they are different and therefore do not identify themselves as carers.'

Some of the agencies reported that young carers were vulnerable to sexual abuse. This could be either in the home or elsewhere. Sometimes, men described as 'undesirable', were brought back home from the pub after closing time. Outside the house, the young carers were seen as older than their age due to the responsibility that they carried. However, they could be looking for a parent figure or a person to care for them, leaving them open to grooming. One of the young carers was described as 'streetwise but vulnerable'.

Although a specific question was asked on dual diagnosis, none of the agencies provided any information on this.

9.2.5 Gaps in services and awareness of other services for young carers

Three of the agencies said that they were not aware of any gaps in the support provided to young carers of substance misusers. Other agencies said that the identification of young carers so that they could receive some services was itself a gap. Another perceived gap was resources. To find the young people and establish

contact was seen as challenging and would require additional resources. When the young people had been found it was felt that they needed a high level of initial contact. This again required a higher level of resources:
'There may be considerable numbers of young carers in this situation who have not been identified.'

Some agencies felt that there should be more support given to the family by the statutory agencies. The support required would be either to help the young person with their responsibilities, or to help the parent acquire skills to run the home.

Agencies said that young people were more likely to ask for help where there was an alcohol problem. This was due to alcohol being a legal substance. Agencies felt that because of this there are probably many substance misuse young carers, who are caring for someone with a drug problem, who are not known to any agency.

Agencies suggested work in schools, awareness raising aimed at young people as well as statutory and voluntary sector staff and increased funding for groups. In commenting on schools, the young carers workers said that some schools were very good and supported the young people. Other schools were not aware of the situation at home. The young carers workers felt that being a carer was detrimental to school work and homework. Some of the young carers were found by agencies after a referral process started because of poor school attendance.

Some of the responses raised the issue of training. One agency said that there were no youth workers who specialised in substance misuse issues. Another agency said that they had found it quite difficult to engage with young people who were substance misuse carers as the young people were very wary of revealing their family situation.

Four of the agencies contacted were not aware of any other agencies that provided support to young carers of substance misusers. Those that did mention other agencies most frequently mentioned the NSPCC project run at the Bure Centre. This provides support to parents who are substance misusers. It provides some support to children where parental / carer substance misuse has an impact on them. Other agencies mentioned included: The Matthew Project, MAP, NORCAS, Youth Services, the Carers Forum and Crossroads.

The agencies not specifically aimed at young people added that a young carer may feel responsible for the adult. This could be for their relapses back into substance misuse or the mental health of the substance misuser. They also commented that younger children can, in extreme circumstances, be used to carry drugs as they would not be suspected or are below the age of criminal responsibility.

Some of the young carers workers did not know how widely known their groups were to other professionals. However they did not feel the need to increase their publicity as resources were already stretched by providing transport to young carers in rural areas. They felt an alternative would be to fund groups in more rural areas of the county.

One agency emphasised that:
'Knowledge, openness and accountability from care organisations supporting these children cannot be overstressed. The long-term nature of this support, i.e. months and years is something services have to address.'

9.3 Information from Young Carers

Six people, who were or had been young carers, provided information on their experiences.

9.3.1 The caring role

The young people said that they had had to take on more responsibility doing things such as shopping, cleaning and cooking, handling the family finances and looking after other siblings and the substance misuser:

'I did a lot of cooking and housework. I would have to wake her up to make sure that she got to appointments such as with the GP. I would have to change the sheets, do washing and things like that. I think that I grew up faster. I was doing GCSEs, housework, shopping and school. Increasingly I was sorting it all.'

'I have had to look after my mum's personal hygiene, feeding her, care for her safety, care for my brothers and sisters. At times I would help my mum to drive to get us home safely when she had been drinking. I have also had to deal with her suicide attempts.'

9.3.2 Other effects of substance misuse in the home

The young people noticed the shortage of money due to the amount being spent on drink or drugs:

'There was never any money because of the amount of alcohol that there was stashed. She was always overdrawn. I remember my mother not having things. We would not have coats in winter because the money had gone on drink.'

The young people in the focus group said that they had experienced abusive behaviour by the parent and arguments between the parents:

'There can be verbal abuse when they are under the influence.'

'There is violence a lot of the time between the adults.'

The young people in the focus group also said that it was difficult witnessing substance misuse and its effects:

'It is hard seeing a parent doing it to themselves.'

'You feel guilty that they are doing it.'

Some of the young people said that they did not feel that they had a childhood. It was a shock to them when they realised that not everyone had to deal with the situations they faced:

'I do not remember a childhood. I remember not knowing how to play properly.'

'You may not find time to be a child – you are not able to play with friends or play with toys on your own.'

9.3.3 Effect on the young carers' health

The young carers said that the caring role had affected both their physical and emotional health:

'I did get depressed about things sometimes. I was worn out and tired a lot of the time.'

'I was taking valium when I was 11. I was dependant on it for a while.'

9.3.4 Effect on the young carers' education

Being a young carer affected their education. The young carers said that whilst they were at school they would be worrying about what was happening at home. This made it hard for them to focus on schoolwork. Some saw school as a break from the

pressures at home. They avoided going home and used the extra time at school to study:
'I think that it made me work harder. If there were free periods I would work in the library rather than come home. I would spend time at school and catch up rather than coming home.'

Some carers said that they were misunderstood at school. It was hard for both other pupils and the teachers to understand the situation they were in. This made it difficult for them to interact socially. Some reported that they had had the mickey taken out of them or were bullied. This increased the likelihood of their caring role remaining hidden. Some said that they were aggressive themselves at school. Some of the young carers reported that schools were not aware of what was happening at home:
'Your behaviour may be misunderstood or taken the wrong way by teachers.'
'Schools do not know. Schools do not look to see why there is poor attendance.'

Some missed out on school altogether:
'I was kept from school.'
'I have stopped going to school as it was too hard.'

9.3.5 Effect on the young carers' friendships

The young people said that friends were not brought home, especially after school:
'I could not bring friends round. I did not know what state my mum or the house would be in. She wouldn't be there or she would be passed out. I would have to clear up after her when she had vomited on the floor. I saw it as normal and thought the same was happening to my friends.'

9.3.6 Effect on the young carers' sexual safety

Some of the young women said that they became sexually active and promiscuous at a very young age. Looking back, they realised that they had put themselves into some vulnerable positions. They said:
'You need a mum at a certain age but they are not there'.
'I was naïve because of my education. I looked for emotional support at a young age. I became sexually active at a young age. I was vulnerable. I did not have any female guidance. I now realise that I took a lot of risks but did not see them as such at the time.'

9.3.7 Inter generational substance misuse

There was some evidence of inter generational substance misuse. One young carer reported that her siblings were involved with substance misuse:
'The oldest brother is dependant on prescription drugs – dihydrocodeine and anti depressants. The other brother has eating disorders with low esteem and depression.'

9.3.8 Sources of support

When the young carers were asked whom they would go to if they needed some help, various relatives were mentioned as well as a friend's mother, social services, a school counsellor, the Matthew Project, the 'Frank' substance misuse website and ChildLine. Some of those in a Young Carers Group mentioned their young carer worker:
'At the high school you can see the school counsellor or the Matthew Project who come into the school. They talk about drugs and offer advice. '

One person, who had been a young carer, reported that she had had help from the church:
'The vicar and his wife helped my mother. They were able to support her and they saw how if affected me. They also helped me leave home. I have had a lot of support from them. They became my family.'

The only other agency she had had help from was the fire brigade:
'I have had support from the fire brigade when she set fire to things.'

One young carer had an escape route:
'As I am older I am able to run away from it. I have places where I can go and stay for a few days. I can then get out of the situation and let the air clear for a little while.'

The young carers who attended a young carers group described the different activities run by the group. They pointed out that:
'We do not talk about things, but we can do if we want to.'

They also commented on its value to them:
'It is a place to get out of the situation and forget it.'
'The carers group is fun.'
'You socialise with people with problems and they will not judge you. You are with people who are in similar situations.'
'I would miss it if I did not go.'

One of the young men said that he would not seek help as:
'I sort it all out myself'.

The young people said that it was a secret world. They were concerned about what people would think of them and what might happen to them if those in authority knew what was happening:
'There is a secret world for young people. You are frightened to ask for help. There is a fear of going into care. The family might be split up or you might be taken away.'

When asked whom they would <u>not</u> want to go to for help, the young people mentioned social services, school, a support group and ChildLine:
'Stuff can happen that you don't want to happen. There can be a loss of control when you contact social services.'
'I would not tell people at school unless I trusted them or there was a special bond. They would try and get involved. They do not understand the situation and I wouldn't want them to.'
'People keep saying that you should go to this group or that group. I would not feel comfortable in support groups. You do not know what to expect and what sort of people will be there.'
'I phoned ChildLine loads of times and you couldn't get through. They did not have anyone to take your call. I was in a bad situation and there was no one to talk to.'

One young carer in Norfolk provided a written statement for some earlier research on their experiences and feelings of being taken into public care. Extracts from this are presented in the box below:

> 'It would have been better for me and my siblings to have stayed at home with daily help from social services because going into care, so far away from family, and being split up from other siblings and my mum, made me more anxious and done more damage, I think, to me and my brothers and mum than staying with her. …..Mum got a lot worse because of the guilt, she became much worse than she ever was and it also broke a bond between a mother and her children, which is OK now but still not as it was, because we were apart for so long. When we got home we felt like strangers. ….From a child's point of view, wherever possible families should be kept together because going into care has caused me and my siblings more problems and damage than being with our mum ever did.' (Written statement by the child of a substance misuser)
>
> Source: Research Plus+ (not yet published)

When asked what help or support they would like, they said that they would have liked to know that there were other people in the same situation as them, information about the substance misuse, its effects and how to deal with it and some moral support. One young man said:
'It is harder than you think. Find someone to talk to. You need to talk to people. Find out if you can get help to take the weight from you.'

Another young man said:
'You just get on with it don't you?'

One young person said:
'I would like a parent'.

9.4 Additional information

Some of the adult carers interviewed for this research said that they had been a young carer for a parent due to the parent's physical or mental health. They then found themselves taking on a caring role again later in life for another member of their family who had a substance misuse problem.

To assist the research, one of the young carers workers provided a copy of a statement by a young carer that had been prepared for a young carers event in 2004. This is reproduced in Box 9.1.

The following pages present seven profiles of young carers. Most of these were based on information provided by the young carers project workers. They illustrate in more detail the issues facing young carers in Norfolk. The names and some details have been changed to protect the identities of the individuals.

Box 9.1 Why are so many children missing their childhood?

Consider this, you are 12, you have a sibling who is four, your mum is a drug addict, what do you do?

- You hide it, for fear that the social services might take you away.
- You protect your little sister, because she can't protect herself.
- You take your mum's benefit book so she has no money for drugs and you can buy shopping, for yourself and your sister.
- You constantly watch over your mum, in case she O.D's or hurts herself.
- You take care of your sister you feed her, dress her, bathe her and put her to bed.
- You take on the role of the parent with all the responsibilities that go with it.
- You stop going out with your friends, in case somebody finds out and anyway you can't leave mum or your sister, who will watch over them?
- You stop going to school because you think that's when your mum is going and getting her drugs and when you do go you constantly get into trouble because you have other things on your mind, you end up permanently excluded, it doesn't matter because your mum's too drugged up to care anyway.
- You think it's your responsibility to stop your mum.
- You become angry, first at your mum, then at yourself, then at the world in general.
- You lose your self esteem and figure you will end up like mum anyway so what does it matter?
- And all this began before your sister was born.

Now consider this: -
A lady came in today, she said she works with young people who help to care for people who are ill/disabled or have drug/alcohol problems, best of all she's not from social services! What do you do?

- You go and see her and tell her you don't really care, but your mum has a drug problem. (A lie and a brave front to hide the pain)
- You start to see her on a regular basis and begin to trust her, you tell her things you can't tell any body else.
- She helps you to understand drugs and why people get addicted to them.
- She helps you to understand that it's not your fault and it's not your responsibility.
- She takes you out and she listens to you, she gives you a break.
- She explains to you how the social services can help and that they need to be involved to help both mum and you and your sister.
- She helps you come to terms with your life, she sticks up for you at meetings with school and social services. This enables you to get a better understanding of your circumstances and get on with your own life.
- Outcome? Your mum is now seeking to go into re-hab. while your sister and you go into temporary foster care, with regular contact with your family. You still see the young carers project worker regularly.

Young Carers Project 2004

Young carer profile 1 – Sadie

Sadie is an 11 year old who lives with her alcoholic mother. She is the youngest of three children, but the two older ones have left home. Her mother is quite open about her drinking – she gets very drunk and literally cannot stand up. Sadie's older sister and brother carry her home from the pub, and Sadie then has to look after her in the home – undressing her, putting her to bed etc. The home is not cared for and Sadie is on the Child Protection Register due to severe neglect.

Sadie was referred to a young carers group by a housing agency two years ago, after the family had become homeless. When she first joined the group she was smelly and dirty and the workers could not tell from her appearance whether she was a boy or a girl. She has had problems at school and she was bullied because she was dirty and poorly dressed. She is now much happier at school and the time spent there is a pleasant escape from her home situation.

She gives the impression that she is tough and able to cope and relates more to the boys in the young carers group. However she is also wary in group situations, due to having been bullied. She talks about her neighbours as if they are part of the family. She tends to make relationships with them which are too intense and this causes the neighbours to back away. Her mother sometimes invites strangers into the house to drink with her and a few months ago Sadie was sexually abused by one of them. This is currently being investigated by the police.

Young carer profile 2 – Peter

Peter is 15 years old. He has two older siblings and two younger siblings. The two younger siblings were taken into long term care before they were of school age. Peter's family has moved frequently – they have had several addresses in Norfolk and elsewhere. His mother originally came from Scotland but had severed ties with her family, as she was ashamed of her lifestyle.

Peter was referred to the Young Carers Project through an Education Social Worker, as he was not attending school. He had been living with his father, but felt left out in his father's new family and wished to return to live with his mother. His mother was not well due to many years of both alcohol and drug misuse (heroin). At the time of the referral, the family had been evicted from council property and Peter, his mother and two older siblings were living in one room with a small kitchen leading off it. Mattresses were propped up against the wall during the day. Shortly after this, Peter's mother was admitted to hospital and it seemed that help in getting better housing would be provided via the hospital social worker.

On release from hospital, Peter's mother had given up drinking. However, after a few weeks, she resumed drinking again and there was considerable violence within the home. By then a school place had been found for Peter and he was making good progress. Peter became friendly with a boy at school and began visiting him and his family frequently. By the time the school summer holidays started Peter was living with this family, as he could not tolerate his mother's drinking, poor health and all the violence.

Social Services became involved at the beginning of the new term when Peter's mother was again admitted to hospital. They were not happy with the family that Peter was living with although he was very happy and felt secure. A social worker began to carry out an assessment but Peter's mother died soon afterwards. Peter could have moved back to live with his father, but he wanted to stay with the family he felt happy with. He stayed with this family until he was moved into foster care.

Peter appears to have missed out on much that is accepted as normal by other teenagers. Both the foster carers and the family Peter had chosen to live with have attempted to widen his horizons.

Young carer profile 3 – Mary

Mary is 16 years old. She supports her alcoholic mother, who binge drinks. Her mother does not acknowledge that she has an alcohol problem and she is also recovering from other illnesses.

Mary's mother does not take good care of herself or her daughter. The family is on benefits and the drinking has depleted the household finances. Mary does all her own washing, she cleans and cares for the home and she ensures that she gets to and from school. Mary also suffers from an eating disorder and is overweight. She receives no support from her mother in dealing with this.

Her mother invites her drinking friends round to the house. As a young woman, this puts Mary a vulnerable situation. It also causes disruption to her sleep pattern, as the drinking is done at night and is accompanied by rowdy behaviour. In her early teens, Mary was groomed by a paedophile as she lacked the emotional support from her mother and so sought it elsewhere. The police and social services were involved.

Mary now has a number of friends and relatives that provide her with informal support. She attends a Young Carers Group and has been encouraged to develop interests outside the home.

Young carer profile 4 – Craig

Craig is 16 years old and lives with his parents and his two younger sisters. One of his older brothers is currently in prison. Both his parents have been involved in drug misuse and drug dealing. His father has been using drugs for over twenty years and is currently receiving treatment for his drug misuse. His mother's drug misuse is not generally recognised. His mother also has older children from an earlier marriage. Some of them are involved with drugs, drug dealing and crime, and their children have been taken into public care.

The home is not cared for and there is little money available for food and clothing. Craig and one of his sisters have to do all the housework. Craig has managed to stay at school but his sisters do not attend, as they could not integrate with the other pupils. Although they are bright, when they did attend school, they experienced both bullying and schooling problems. One of his sisters was violent. The school treated these problems at face value and did not appear to be aware of the drug and other issues within the home.

One of his sisters has attended a young carers group for a number of years. Craig started attending a young carers group two years ago. For the first 18 months he was very withdrawn, he would not speak to anyone and did not participate in any of the activities. He now joins in the activities but still does not speak much.

Young carer profile 5 – Tracy

Tracy is 17 years old. She has a younger brother and sister. Their mother has had long-term mental health problems and periods of binge drinking. They lived with their mother but have had many periods of their life in foster care. Over the years, Tracy provided substantial care for her mother and younger siblings and became withdrawn and secretive. She found it difficult to make friends and twice joined a young carers support group, but never stayed for more than a few sessions. All the children kept in touch with their foster carer, who also gave their mother a lot of informal support.

Around the time of Tracy's GCSE exams her mother's drinking escalated, mainly because she had a new partner who also drank heavily and was violent. The children had been on and off the At Risk Register and there was now considerable concern as the new partner had hit both of the younger children. They moved back into foster care and their mother attempted to commit suicide. Tracy found her when visiting the house. Her mother made a good physical recovery but within a month she was left for dead after several days of drinking. Her partner, fearing the worst, had run away.

Tracy's mother is now in a persistent vegetative state. Tracy and her sister now live separately with different relatives and her brother lives with the original foster carer. Tracy started college but couldn't settle and is angry with her mother. She no longer visits her at the nursing home.

Young carer profile 6 – Darren

Darren is 18 years old. His mother is a long term heroin user. She also has mental health difficulties and receives support from a CPN. For some time, Darren was living with his birth father, but this arrangement broke down and he went back to live with his mother. Darren is also a heroin user. His mother's most recent partner is a drug dealer and he supplied both Darren and his mother with heroin. During the research period, the partner was convicted of burglary and sentenced to custody. Darren's mother now depends on him to fund and provide for her habit. This involves him in crime. His mother appears to be completely incapable of supporting and managing herself. This is a repeating pattern of behaviour that he has experienced most of his life. At times he is also required to inject his mother.

Darren has two younger siblings and, in the past, he had to help with caring for them. They were taken into care and are now being offered for adoption. This has undermined his recovery. Due to his offending behaviour, he came to the notice of the criminal justice system and was subsequently referred to a drug treatment service. Darren tends to put his mother's needs before his own and this undermines efforts to help him. For example, he was considering going into rehab to deal with his own drug use, but he could not cope with the thought of leaving his mother on her own. He is described as a pleasant and engaging young man.

Postscript: Darren is now in prison himself. He is off the drugs and proving to be a model prisoner. There are plans to provide him with supported accommodation and work opportunities in another county when he is released.

Young carer profile 7 – Fred

Fred is 18 years old. As far as he is aware, his mother has always drunk a lot. He now realises that he cared for his mother, who is an alcoholic, throughout his secondary schooling. His father spent most of his time at work. Fred looked after the house, including the shopping and the cleaning. He would also ensure that his mother attended appointments and he looked after her when he came back from school. Sometimes she had passed out by the time he got home. At times he would be tired from the extra work that he had to do. He did not bring friends home after school.

He feels that he "got by" with looking after his mother, but, looking back, he now realises that it could have been much different. He did not know there was anyone out there who could support him. No one at school was aware of his home situation and he only told one or two close friends.

He feels that he has grown up faster than other young people and he now has a very close relationship with his father. He does not see his mother, who is thought to be living in another town with a drug user she met in rehab.

9.5 Summary

- There are 25 young carers groups across Norfolk.
- Eleven completed questionnaires were returned from 19 young carer groups. A response rate of 58%.
- The Carers Grant was an important source of funding for the young carer groups and all agencies that apply for a Carers Grant have to work to agreed standards.
- Eight of the agencies did not identify any 'national or local standards or protocols' that they worked to.
- Only one agency was aware of any local or national research or reports on the needs of young carers of substance misusers.
- The agencies provided considerable information on the main issues faced by young carers of substance misusers and the barriers to providing support to them. Many of the issues mentioned reflected the issues identified in national research, as outlined in Section Three.
- All but three agencies identified gaps in current service provision and made suggestions to improve services for young carers.
- Four of the agencies were not aware of any other agencies that provided support to young carers of substance misusers.
- Six people, who were, or had been, young carers, provided information on their experiences. These included:
  - The extra domestic responsibilities they had to take on, including care of their siblings and the substance misuser
  - Other effects of substance misuse in the home
  - The effect on their physical and emotional health, their education, friendships and sexual safety
  - The potential for inter-generational substance misuse.
- The young carers identified sources of support and which agencies they would not wish to contact.
- A statement by a young carer and seven profiles of young carers, illustrated in more detail the issues facing young carers in Norfolk.

Section Ten
Conclusions and Recommendations

10.1 Introduction
This section sets out the conclusions and recommendations based on the findings of the research.

Government policy for carers includes substance misuse carers. The survey of agencies revealed that there is provision for substance misusers and for carers in Norfolk, but little provision for substance misuse carers specifically.

10.2 Carers' initial information needs
Substance misuse carers deal with complex problems related to the substance misuse. This is often accompanied by stigma and shame for the substance misuse carers. The illegal nature of drug misuse creates additional difficulties.

Substance misuse carers want information. This includes: information on drugs and alcohol and their effects on the user, information on drug and alcohol treatment processes, advice on how to handle the substance misuser – to help rather than hinder the work of professionals, advice on how to look after themselves and information on where they can go to get help and support. Many substance misuse carers had difficulty in finding out this information.

It is recommended that:
- An Information Pack is developed, which details sources of information and support available in Norfolk and nationally, including relevant websites and helplines.
- The Information Pack is made available through libraries, community centres, local projects and other public places.
- The Information Pack is made available to all front line staff in key agencies that come into contact with substance misuse carers, including drug and alcohol treatment agencies, carers' organisations, the police, mental health staff, voluntary and community projects, religious centres, social services, the CAB and probation.
- The next edition of the DAAT booklet 'Drug and Alcohol Services in Norfolk' contains more information on sources of information and support for substance misuse carers.
- More information on sources of information and support for substance misuse carers is included on websites, including the Norfolk DAAT and the Heron website.

Other recommendations to increase substance misuse carers' awareness of the information and support services available are detailed below.

10.3 Carers' assessments
Few substance misuse carers were aware of their entitlement to a carers' assessment and only one person interviewed had actually received one. Substance misuse social workers reported that they currently undertake only a very limited number of carers' assessments. Norfolk County Council Social Services has been piloting the use of Carers Grant funding to routinely provide assessments in relation to carers of older people and carers of people with a physical disability.

It is recommended that:

- A system is established to routinely provide assessments of carers of substance misusers. Where possible, this should be linked with the assessment of the substance misuser. However, lack of engagement by the substance misuser should not prevent a carer's assessment, as the provision of services to the carer can lead to engagement of the substance misuser in treatment. It is suggested that this commences in one or two drug and alcohol treatment agencies as a pilot, prior to wider application.

10.4 Carers' support and training needs

Carers need support. This includes support with caring for the substance misuser, dealing with the problems related to the substance misuse and with caring for themselves. Some of the substance misuse carers did not receive any support for many years, this was especially true for those caring for problem drinkers.

There is no single service that will meet every carer's need at all stages of the caring process. Some people benefited greatly from attending a self help / support group, but these do not suit everyone. Others welcomed ongoing support through a substance misuse treatment service. Some preferred using a generic service, such as their GP or a counselling service. Others received some support through mental health support agencies or mental health carer groups. They also contacted a wide range of other agencies for help and support. Some needed a break from the pressures of caring

Substance misuse carers stressed the importance of anonymous, confidential support such as that provided through telephone support from a worker or a confidential helpline such as the Matthew Project helpline or the Norfolk Carers helpline.

It is recommended that:

- A range of services are developed which include provision of information, individual or family counselling, self help / support groups, respite care and confidential helplines.
- Training opportunities are provided for substance misuse carers to learn more about substance misuse, how to support substance misusers and themselves and sources of support.

10.5 Direct funding to adult substance misuse carers

Caring for substance misusers often involved the substance misuse carers in extra costs, e.g. caring for a substance misuser's children. One or two of the substance misuse carers had been unable to attend a support group due to the cost of transport.

It is recommended that:

- Financial assistance for carers, available through the Carers Grant, is publicised to substance misuse carers.

10.6 Funding for agencies that work with adult substance misuse carers

Most of the statutory and voluntary drug and alcohol treatment agencies that currently undertake some work with adult carers of substance misusers receive no specific funding for this work. Other agencies that currently work with adult carers of substance misusers have no specific funding or only short term funding. Self help /

support groups are currently self financing. There are only a limited number in Norfolk, especially for carers of problem drug users.

It is recommended that:

- Agencies are specifically commissioned to undertake work with carers of substance misusers and ring fenced funding is made available for this on a secure basis.
- The Norfolk DAAT discusses with the self help / support groups ways to expand the number of these groups and what funding, if any, would assist this.

10.7 Primary care services

The people that the substance misuse carers had the most contact with were their own and / or the substance misuser's GP. Primary care staff play a key role in identifying and supporting substance misuse carers. GPs and other primary care staff could also be an important route for providing information to substance misuse carers and signposting them to other services.

It is recommended that:

- GPs and other primary care staff continue to provide support to substance misuse carers.
- GPs and other primary care staff provide information to substance misuse carers on other sources of information and support and then encourage them to make contact with these agencies.

10.8 GP Carers' Registers

In line with government policy, some GP surgeries in Norfolk have started to develop registers of carers. None of the substance misusers contacted for the research had been invited to be on a carers' register. Including carers of substance misusers on these registers could be an important step in recognising their existence and needs.

It is recommended that:

- Carers of substance misusers are included in GP registers of carers.
- The wording of the publicity displayed in the surgery and the actual forms to be completed by individual carers make it clear that substance misuse carers are included.
- GPs and other primary care staff encourage carers of substance misusers to go onto the registers.
- The information on the registration form includes a section on whether the carer is willing to be contacted by agencies wanting to consult with and involve carers in the development of services. If so, they are also encouraged to register with the Norfolk Carers' Voice.

10.9 Carers' relationship with agencies treating the substance misusers

Substance misuse carers wanted to be treated with respect by professionals and to be seen as part of the team helping to tackle the substance misuse. They wanted to be able to aid rather than hinder any treatment being provided. However many carers experienced difficulties in obtaining information on the treatment processes used by agencies. Due to confidentiality issues, they were even less likely to be given information on any work being done with the substance misuser, unless the substance misuser had given express permission for this to happen.

It is recommended that:

- Information is provided to carers on the treatments offered by different agencies and the recovery process for substance misusers.
- Ways of actively involving the substance misuse carers in the treatment process are explored.
- Staff in substance misuse treatment agencies are encouraged to provide what information they can to substance misuse carers and to clearly explain why they cannot provide more.

10.10 Mental health issues and dual diagnosis

95% of the substance misusers were reported to have problems with their emotional / mental health, and a significant number had recognised mental health problems. This increased the pressures on the substance misuse carers. Some substance misuse carers also experienced considerable difficulty and frustration in obtaining a mental health diagnosis for the substance misuser and services to treat any mental health problems.

90% of the substance misuse carers reported that the person's substance misuse had effected their own emotional / mental health, and a significant number had recognised mental health problems.

In line with government policy, work to develop services for people with dual diagnosis (substance misuse and mental health) is currently in progress in Norfolk.

It is recommended that:

- Substance misusers are included as a target group for mental health promotion work, as part of implementing Standard One of the National Service Framework for Mental Health.
- The carers of substance misuse are included as a target group for mental health promotion work, as part of implementing Standard One of the National Service Framework for Mental Health.
- Substance misuse carers are consulted with and involved in the development of services to respond to dual diagnosis.
- Substance misuse carers, caring for someone with a mental health problem, are provided with information on how to care for someone with mental health problems.
- Substance misuse carers, caring for someone with a mental health problem, are provided with information about mental health support services and associated initiatives.

10.11 Good practice standards

The government has established national quality standards for local work with carers. The King's Fund has published a guide to these (Blunden, 2002) and they are an integral aspect of all applications for the Carers Grant in Norfolk. More recently some of the national substance misuse carers agencies have published some good practice guidance and quality standards for work with substance misuse carers (Rattenbury and Linnett, 2005). Many of the key agencies that work with, or come into contact with, carers of substance misusers did not report that they follow any national or local standards for working with substance misuse carers.

It is recommended that:

- DAAT commissioners examine these standards with a view to including them in future contracts and service level agreements.
- These standards are brought to the attention of agencies that work with, or come into contact with, carers of substance misusers.

10.12 Information and training for agencies

Carers of substance misusers are in contact with a range of agencies, prompted by issues related to the substance misuse. They could all play a part in the provision of information to carers. Although many of the agencies contacted were aware of the issues facing substance misuse carers, they were not necessarily well equipped to meet their needs.

It is recommended that:

- Key agencies that have contact with carers of substance misusers are sent a copy of the report 'We Count Too' (Rattenbury and Linnett, 2005) and a summary of this research.
- Key agencies that have contact with carers of substance misusers are invited to the follow up conference related to this project.
- All front line staff in key agencies that come into contact with carers of substance misusers are provided with the Information Pack on sources of information and support for substance misuse carers.
- Training is provided to key agencies and workers in contact with substance misuse carers. The level of training provided is tailored to the level of work to be undertaken with substance misuse carers. The training includes training in quality standards and information sharing.
- Training is also provided to students, on health, social work and carers' courses, on substance misuse carers, their support needs and ways to consult with and involve them in the planning and provision of services.
- Substance misuse carers are involved in the planning and provision of this training and are themselves trained, paid and supported to do this.

10.13 Hard to engage groups

National research and the experience of this research has identified that particular groups are less likely to make use of support services for substance misuse carers. These include:

- men
- gay, bisexual, lesbian and transsexual people
- travellers
- black and minority ethnic carers (including refugees, asylum seekers and migrant workers).

It is recommended that:

- The Norfolk DAAT, in consultation with relevant agencies, considers and develops appropriate methods to contact and support substance misuse carers from groups less likely to engage with existing support services.

10.14 Carer consultation and involvement

There are national policies and initiatives to involve substance misuse carers in the provision of services for themselves and the substance misusers, and to have a say in the development and organisation of substance misuse and carer agencies. Most of the substance misuse carers, who participated in the research, were keen to be consulted with and involved in the provision of services for themselves and the

substance misusers. At the time of the research, only three of the 160 carers registered with the Norfolk Carers Voice were substance misuse carers.

It is recommended that:

- Carers of substance misusers, who participated in the research, are invited to the follow up conference related to this project.
- Ways to consult with and encourage the involvement of substance misuse carers are explored at the follow up conference.
- Contact is made with the organisers of self help / support groups for substance misuse carers to explore this further.
- Further consultation events are organised, as appropriate.
- Substance misuse carers are encouraged to register with the 'Norfolk Carers Voice'.
- Substance misuse carers are involved in the planning and development of services for substance misuse carers.
- As part of this, substance misuse carers are encouraged to be involved in the work of the Norfolk Carers Partnership and in the planning and development of the next Carers Action Plan for Norfolk.
- Substance misuse carers are involved in the planning and development of drug and alcohol services.
- Substance misuse carers are involved in the recruitment of staff to work in drugs and alcohol treatment agencies, carers' agencies and other agencies that provide support to substance misuse carers.
- Training is provided for substance misuse carers to enable them to be consulted and involved in the planning and provision of services and the recruitment and training of staff.
- A support system is established, including financial support, to enable substance misuse carers to be consulted and involved in the planning and provision of services and the recruitment and training of staff.

10.15 Young Carers

Young carers of substance misusers receive support through the countywide young carers projects. The projects cater for all types of young carers and focus on providing young carers with a break from caring. Many young carers are hidden, they are often not referred to a young carers project until there is a crisis or a child protection concern which comes to the notice of agencies. Schools are sometimes, but by no means always, aware of substance misuse young carers. Some work is currently undertaken in primary and middle schools. In the past, a young carer worker also went into secondary schools and talked about young carers. This helped identify young carers, who were not in crisis but needed support.

It is recommended that:

- A young carers worker, specialising in substance misuse young carers, is appointed to work alongside the general young carer workers.
- This worker works with both the general young carer workers and, where appropriate, the young substance misuse carers themselves.
- More one to one support and counselling is provided to substance misuse young carers.
- Action is taken to identify more substance misuse young carers before there is a crisis or a child protection concern. Schools could play a part in this.
- The number of young carer projects is increased to cater for more substance misuse young carers.

- Ways to report the findings of this research to substance misuse young carers are identified and acted on.
- Ways to consult with and encourage the ongoing involvement of substance misuse young carers in the planning and development of services for them are explored.

10.16 Substance misuse carers who work for substance misuse or carer agencies

A significant number of staff that work for substance misuse and carer agencies are also substance misuse carers in their personal life. It can be difficult for them to use services that are available through their own agency and sometimes other agencies, due to confidentiality issues.

It is recommended that:

- Substance misuse carers that work for substance misuse and carer agencies have access to confidential support outside of their line management and their own project.

10.17 Action Plan

This research has generated a considerable number of recommendations.

It is recommended that:

- A 3 to 5 year Action Plan is drawn up to implement the recommendations, with a built in annual review process.

A comment by one of the carers interviewed summed it all up as follows:

'This is so good. Something must take off. An honest open approach is needed about addiction because it is hidden. It crosses ages, class and race. It is getting worse with the young people. It is now not a minority. There are too many young people who are going down horrible roads. You have to talk about it and create a generation that will talk about it. You cannot cope well if there is secrecy.'

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Glossary of Abbreviations

ACPC	Area Child Protection Committee
CAB	Citizens' Advice Bureau
CARATS	Counselling, Assessment, Referral, Advice and Throughcare Services. CARATS teams work in prisons with prisoners who have substance misuse problems
CPA	Care Programme Approach
CPN	Community Psychiatric Nurse, now called a community mental health nurse
DAAT or DAT	Drug and Alcohol Action Team or Drug and Alcohol Team
NELM	North Earlham, Larkman and Marlpit area of Norwich
NIMHE	National Institute for Mental Health in England
NTA	National Treatment Agency for Substance Misuse
NHS	National Health Service
NYCS	Norfolk Youth and Community Service
PCT	Primary Care Trust
QuADS	Quality in Alcohol and Drug Services

Appendix
List of Organisations Contacted

A1.1 Agencies that responded to the email survey

- ADAPT
- Alcohol and Drug Service, Norfolk and Waveney Mental Health Partnership NHS Trust - Bure Centre, Colegate Service
- Alcohol and Drug Service, Norfolk and Waveney Mental Health Partnership NHS Trust - Bure Centre, Unthank Road
- Alcohol and Drug Service, Norfolk and Waveney Mental Health Partnership NHS Trust - Victoria Street Alcohol Service
- Alcohol and Drug Service Norfolk and Waveney Mental Health Partnership NHS Trust - substance misuse social workers – three responses
- Broadland Mental Health Support Services
- CADS, West Norfolk
- Contact NR5
- Crossroads – Caring for Carers – response from two independent schemes
- Families Anonymous – response from one local group
- Focus, Bury St Edmunds
- Great Yarmouth and Waveney Mind
- Impact
- Linking Together
- NORCAS Counselling Service
- Norfolk Carers Helpline
- North Norfolk Mental Health Support Services
- Norwich & District Carers Forum
- NSPCC
- South Norfolk Mental Health Support Services
- T2
- The Matthew Project – four responses
- West Norfolk Carers Association
- West Norfolk Mind
- West Suffolk Drugs and Alcohol Service, Bury St Edmunds
- 11 staff from young carers projects across Norfolk

A2. Other Norfolk agencies contacted during the research

- Al Anon Family Groups
- Alcoholics Anonymous
- Crossroads – Caring for Carers – other independent schemes
- Families Anonymous – other local groups
- Family Matters
- Hebron Trust
- ISU – Involving Service Users
- MAP – Mancroft Advice Project
- NELM Community Support Workers
- NORCAS Great Yarmouth
- NORCAS Homeless Outreach Service
- NORCAS Lowestoft
- Norfolk and Norwich Race Equality Council and 20 black and minority ethnic groups in Norfolk
- Norfolk Constabulary
- Norfolk County Council Library Services
- Norfolk County Council Social Services – Children's Services
- Norfolk County Council Social Services – Young Carers Projects
- Norfolk County Council Social Services – Research
- Norfolk Disability Information Service
- Norfolk Drug and Alcohol Action Team
- Norwich and District Mind
- Norwich Primary Care Trust
- Overcomers Dependency Support
- PALS, Norfolk and Waveney Mental Health Partnership NHS Trust
- Pottergate ARC
- Pulham Market Surgery
- Rethink
- The Alliance Advocacy for Drug Treatment
- 'The Communicator'
- West Norfolk PCT
- Yesu, Sheringham
- Other staff from young carers projects, that did not complete a questionnaire

A3. National organisations contacted included:

- Adfam
- Alcohol Concern
- Audit Commission
- Carers National Association
- Carers UK (Formerly the Carers National Association)
- DrugScope
- GO East
- National Association for the Children of Alcoholics
- NTA – National Treatment Agency for Substance Misuse
- Nottingham City DAAT
- PADA – Parents Against Drug Abuse
- Princess Royal Trust for Carers
- Rethink national office
- School of Health and Related Research, Sheffield University
- Young Carers Research Group, Loughborough University Centre for Child and Family Research