

Mental Health & Alcohol Misuse Project Briefing 3: Caring for Carers

Carers provide care and assistance to another person who is sick, disabled or elderly. Carers also help people experiencing problems with mental illness and/or substance misuse. In response to the difficulties and demands often associated with caring, a number of recent policy initiatives have sought to increase the provision of help and support available to carers.

This briefing outlines policy and practical initiatives concerning carers of people with mental illness, including Standard six of the Mental Health National Service Framework (MHNSF), *Caring about carers*.

Given the links between alcohol misuse and mental health problems, it is important that alcohol services are positively involved in the development of carer support services and play a role in identifying and working with carers. This paper offers suggestions to increase the involvement of alcohol services in carer initiatives and explores some models of carer support.

Summary: The briefing at a glance

- The responsibilities of caring make a number of demands on the lives of carers, affecting them financially, physically, socially, and mentally. A recent survey showed that carers suffer from high rates of anxiety and depression.
- The MHNSF aims to ensure that carers for people on Care Programme Approach have their own needs assessed and met by health and social services.
- Alcohol services are not primarily responsible for assisting those caring for people with severe mental illness. However, alcohol services may encounter carers of people with concurrent alcohol *and* mental health problems.
- Alcohol services can be positively included in carer initiatives, such as the development of referral protocols and links between services, and involvement in the process of evaluating carer support services.
- Alcohol services should be commissioned to provide specialist programmes to support family members of people with substance misuse problems. Carers' education and training programmes should include links to alcohol services.



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The Mental Health & Alcohol Misuse Project (MHAMP) provides fact sheets, a newsletter and web pages aimed at sharing good practice between clinicians and professionals working in the mental health and alcohol fields. MHAMP promotes the inclusion of alcohol in strategies developed for the Mental Health National Service Framework, and updates the mental health and alcohol fields on current mental health and alcohol-related issues.

For more details contact:
Slade Carter,
Mental Health Policy Officer
020 7922 8657
scarter@alcoholconcern.org.uk

Alcohol Concern
32-26 Loman Street
London SE1 0EE
www.alcoholconcern.org.uk



Introduction

Who are carers?

Carers are people who look after or provide care or some regular service to another person who is sick, disabled or elderly, other than financial help only or assistance provided in a professional capacity (Office for National Statistics [ONS] 2002). Carers, who may or may not live with the person being cared for, include people who provide care for those with mental illness and/or alcohol problems.

The 'carer support workers' referred to in this paper are health or social care professionals who provide specialised support to carers of people with mental health problems (Department of Health 2002).

This paper explores the provision of care and assistance to carers themselves, in particular, carers of people with mental health problems and alcohol problems. The briefing also looks at opportunities for alcohol services to increase their involvement with carers of people with a drinking problem, by, for example, working with families of drinkers.

This paper outlines four primary issues:

1. The current policy agenda to look after the needs of carers ("caring about carers")
2. Opportunities to involve alcohol services in carer initiatives
3. Opportunities for alcohol services to increase their engagement with carers by working with the families of problem drinkers
4. Models of support for carers.

Facts about carers

- One in eight people in Britain is a carer (DoH 1999a)
- Most carers (41%) are likely to be aged between 45 and 64 (DoH 1999a)
- About half of those people with severe mental illness live with family or friends, and many others receive considerable support from them (DoH 1999b)
- The responsibilities of caring can impact negatively on carers' mental health, often contributing to high levels of anxiety and depression (ONS 2002)
- The families of individuals with severe mental illness may experience demanding behaviour, extra financial burdens, restrictions on their social and family life, and occasionally a risk to their own safety (Kuipers 1993, cited in DoH 1999b)
- Of the estimated total 5.7 million people who are carers in Great Britain, 1.7 million devote *at least* 20 hours a week to caring (DoH 1999a).

Policy Frameworks

National Strategy for Carers – Caring about carers

In recent years, a number of initiatives have been implemented to help carers by providing direct assistance, increased staffing (of carer support workers), and financial support. The Carers (Recognition and Services) Act 1995 gave people who provide "substantial care on a regular basis" the right to request an assessment from social services. However, there is evidence to suggest that the implementation of the Act has achieved mixed success. Assessments of carers' needs are not always carried out and, while some carers are offered sensitive, practical and emotional support, others receive little or no help at all (DoH 1999b).

Further evidence indicates that carers of people with severe mental illness are not always receiving the services they need to support them, or to maintain their own good health. In a Social Services Inspectorate report, carers of people with mental health problems were especially critical of how little they were consulted about care plans for service users, how their own needs were not assessed, and how little support they received (Social Services Inspectorate 1998, cited in DoH 1999b). In addition, few authorities had implemented the Carers Act within their mental health services when inspected in 1999 by the Social Services Inspectorate (Social Services Inspectorate 1999, cited in DoH 1999b).

To improve information, support and assistance for carers, the Government launched a National Strategy for Carers, *Caring about carers*, published in February 1999. The strategy outlines a number of measures to improve the conditions of carers, including:

- Measures to engage carers as partners in planning services and assistance for carers.
- Extra funding to enable carers to take a break from caring. £140 million was allocated to local authorities between 1999-2000 and 2001-2002 for this purpose.
- The requirement that health authorities and local authorities bring together the organisations in their locality which assist carers to assess carers' needs and how local support services should best be provided (DoH 1999a).

Local support for carers is often provided by voluntary organisations through carers' centres, whose activities may include:

- Information and advice about issues affecting carers
- Emotional support and befriending schemes
- Training for carers
- Practical support, including assistance with daily tasks
- Carers' support groups
- Social and recreational activities
- A break from caring responsibilities
- Advocacy, helping carers access benefits and services (DoH 1999a).

The Mental Health National Service Framework (MHNSF)

Standard six of the Mental Health National Service Framework (MHNSF), also called *Caring about carers*, aims "to ensure health and social services assess the needs of carers who provide regular and substantial care for those with severe mental illness, and provide care to meet their needs" (Department of Health 1999b: 69).

The MHNSF indicates that:

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

- Have an assessment of their caring, physical and mental health needs, repeated on at least an annual basis
- Have their own written care plans which is given to them and implemented in discussion with them" (DoH 1999b: 69).

To achieve Standard six of the MHNSF, local services need to pay greater attention to the needs of people who care for someone with a mental health problem. As well as assessing carers' needs and producing care plans for carers themselves, local networks to support carers should be developed (DoH 1999b).

The MHNSF recommends the following organisations should be responsible for the implementation of Standard six:

- Lead organisation: local authority
- Lead officer: Director of social services
- Key partners: health authority, primary care trust, including GPs, NHS trust, independent sector providers, service users and carers (DoH 1999b).

Developing services for carers and families with mental illness

In November 2002, the Department of Health published *Developing services for carers and families with mental illness*. This guidance aims to help local mental health services develop support services for carers of people with mental health problems. The document contains guidance on developing and sustaining mental health carer support services.

Although Standard six of the MHNSF and this guidance are aimed primarily at carers of people with severe mental health problems on the Care Programme Approach (CPA), many carers provide significant care to people with mental health problems who are *not* on CPA. The principles in the guidance are also relevant to this wider group (DoH 2002).

Commissioners and providers of health and social care mental health services are responsible for the implementation of the guidance, with Primary Care Trusts also playing an important role in identifying and supporting carers of those with mental health problems. The carer support services referred to in the document are for people involved in the care of a person with a severe mental illness. To be considered a carer, a person does not have to live in the same household as the person being supported.

Carer support services should provide:

- Support and advice, including advocacy
- Information
- Breaks
- Access to appropriate interventions, including training.

The location of carer support workers should be locally determined, however, they should be placed in settings where they are visible and accessible to carers and referring agencies. Possible locations could include a community mental health team, carers centre, GP surgery, or voluntary sector agency.

Resources for an additional 700 carer support workers will be made available through NHS mental health funding allocations. The carer support workers will help increase breaks available to carers and strengthen carer support networks. Commissioners will decide how to allocate these resources locally.

Carer support services are complementary to existing services and part of the overall local system of mental health and social care provision. Carer support services will need operating and referring protocols agreed with all relevant agencies. These protocols should include the following aspects:

- What the service is aimed at
- Accessing the service
- Linkages between the service and local mental health care coordinator and the cared for person's care plan
- The role of the service in helping carers access short breaks (DoH 2002).

Since alcohol services may be considered a relevant link agency, carer support services should make their service known to local alcohol services.

Alcohol Services and Carers

While alcohol services are not primarily responsible for ensuring that carers of people with severe mental illness are themselves supported, alcohol services may frequently encounter carers of people with mental health and alcohol problems. In addition, carers of people with alcohol (and/or mental health) problems may themselves develop mental health problems or distress: for example, the existence of serious alcohol problems is associated with stress for close family members, stress which is often severe and protracted (Orford et al. 1998a; Jackson 1954, cited in Copello et al. 2000). Relatives in these circumstances have a high risk of developing mental health problems as a result of the stress experienced, and show high rates of trauma and attendance at the doctor (Svenson et al. 1995; Roberts and Brent 1982, cited in Copello et al. 2000).

A number of alcohol service clients may have differing degrees of mental health problems, and some clients (including dual diagnosis clients) may be cared for at home by friends or family. These carers may benefit from the support of a carer support service.

Including alcohol services in carer initiatives

The key players responsible for implementing carer strategies for carers of people with mental illness – PCTs, mental health services, social services and local authorities – should include alcohol services in carer initiatives through a number of measures, such as:

- *Developing services for carers and families with mental illness* ('the guidance') indicates that the impact and success of carer support services should be evaluated. Alcohol services could be included among stakeholders engaged in this evaluation process.
- Operating and referral protocols to carer support services should include *relevant agencies*. Alcohol services could be included as participant in these protocols.
- Carer support services should promote themselves and their links to other agencies. Promotional strategies could include alcohol services, their clients and clients' carers.
- Carer support workers might include a person responsible for assisting carers of people with alcohol and drug-related problems (as discussed below).
- Alcohol services could be commissioned to provide specialist programmes to support family members of people with substance misuse problems (discussed below).
- Carers' education and training programmes could be promoted and funded to include alcohol services.
- The guidance states: "agencies should, wherever possible, work together to ensure that a carer has one assessment which will enable them to access all services" (DoH 2002). Those responsible for conducting the assessment (most probably in a mental health service) could include screening for alcohol problems, and include the possibility of accessing alcohol services, if the carer has an alcohol problem.

Working with families

Evidence shows that agencies working with families of people with substance addictions can benefit the drinker or drug user and the family of that person (Copello & Orford 2002).

In some instances, family members may be supporting (that is, “caring for”) a person with substance misuse problems. In spite of the potentially useful role of families, substance misuse service delivery is focused on the *individual* drinker or drug user, with families and other members of the user’s social network playing a very peripheral role in service engagement (Copello & Orford 2002).

The lack of service engagement with families can be very pronounced. A survey conducted by Copello and Orford monitored all contacts across the community alcohol services provided by one of the largest providers of alcohol agencies in the UK. The survey aimed to establish whether family members affected by alcohol problems were seen in routine practice. Out of 174 client contacts, family members were seen as clients in their own right in only five cases (2.8%), with family members involved in couple interventions in a further three cases (1.7%) (Copello & Orford 2002).

Given both limited resources and the evidence in favour of family interventions and involvement, Copello and Orford suggest a number of measures be considered by both service providers and commissioners:

- Models of alcohol and drug problems need to place the role of the social environment as central and as important as that played by individual factors.
- The base of treatment should be broadened to consider the family a legitimate unit for intervention.
- Both commissioners and service providers need to pay more attention to the broader social costs associated with substance misuse. Resource costs such as additional health and welfare demands made by affected family members are significant. But the social costs of the impact of addictions on family members (such as substance-related family violence) are also important (Copello and Orford).

Copello and Orford suggest altering the focus of treatment from the individual to the social context within which the addictive behaviour takes place, placing an increased emphasis on the family, and engaging with the family in interventions (Copello and Orford 2002).

Models of Carer Support

Alcohol services working with families

As evidenced above, many alcohol services engage with the individual problem drinker, and do not engage the family of that person. Alcohol services could increase their level of support for families of problem drinkers and work with them to help the drinker.

Some alcohol services are engaging with families, which have found that, just as service users have needs, so too do families. **Residential programmes** offered to family members of people misusing substances enable participants to develop self-awareness, share experiences, and learn how to help themselves. Lectures and workshops are held on issues related to alcohol and drug problems.

Clouds in Wiltshire offers a residential family programme aimed at people affected by another person’s substance misuse. For more information, contact Nick Barton, Chief Executive, on 01747 830 733; email nick.barton@clouds.org.uk

Alcohol services can also provide **day support and counselling** to the families and significant others of problem drinkers. Some alcohol services meet with family members to discuss their needs and concerns. In some instances, other relevant services may be

invited to meet with the family, including mental health services and Social Services, to explore the family's values, goals, strengths and needs.

Day services offered to family members may include counselling individuals and couples, play therapy for children, exploration of coping strategies and means of engaging with other services, and risk and resilience (including measures to reduce the risk of harm).

The Family Alcohol Service, Camden and Islington, provides help to families and significant others of problem drinkers. For more information, contact Ann Waller, Manager, on 020 7383 3817; email awaller@nspcc.org.uk

Substance misuse carer support workers

Some local areas offer carer support for people who care for those with a substance misuse problem. A carer support coordinator can organise support including respite and home care, and provide the carer with information (such as how to access financial assistance available to carers). Carers might approach this service through a variety of sources and referrals including GP, hospital and self-referral. Clients might be visited in their homes or other services such as GP surgeries and drug and alcohol services.

The Community Alcohol and Drugs Advisory Service (CADAS) in Dorset offers a drug and alcohol carer support programme. For more information, contact Paul Phillips, Community Care Officer, on 01305 265 635.

Carers' training and education programmes

Alcohol and mental health services may know of clients who are being provided with regular care by another person. These carers may benefit from attending a carers training and education programme in their area. This, in turn, may improve the life and condition of the person being cared for and attending your service.

Education programmes are available for carers of people with mental illness. Such programmes may cover information about mental illness and the teaching of skills to help carers deal more effectively and confidently with their role. The training may include issues such as understanding mental illness, coping strategies for dealing with the illness, information on treatment plans, assessment, communication and managing symptoms, and how carers can better look after themselves.

A range of people, including carers themselves, carer support workers, family workers, social workers, and CPNs may provide the training.

Carers may also be given the opportunity to meet with other mental health and community service professionals such as psychologists, psychiatrists, police and pharmacists.

If you do not currently offer carer training and support, check with your local PCT, Trust or Social Services, which may have purchased such a programme for your area.

One such carers' education scheme is the Carers' Education and Support Programme (CESP), run by the mental health charity Rethink. This 10-session course provides training for carers of people with severe and enduring mental illness, and will shortly include a component on understanding dual diagnosis.

For **more information** on CESP, contact Andy Payne, Service Manager, tel. 020 7837 740; email cesp@rethink.org

Resources

Involving carers in strategies for carers

Carers Northern Ireland has produced a document, *Involving and consulting carers: A guide to giving carers an effective voice*. The document is designed for both professionals and carers and is available online at the Carers Online website at: <http://213.130.44.59/carersuk/downloads/Involveconsult.pdf>

Carers UK is a charity that provides support to anyone who is a carer.

For more information, see the Carers Online website:

<http://213.130.44.59/carersuk/>

Adfam is a charity working with families of drug and alcohol users.

Website: www.adfam.org.uk

Policy documents

Caring about carers: www.doh.gov.uk/pub/docs/doh/care.pdf

Developing services for carers and families of people with mental illness:

www.doh.gov.uk/mentalhealth/devservcarers.pdf

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