

"Until recently, I did not know support was there for carers!"



Who cares?

The experiences of mental health carers accessing services and information

June 2003

rethink
severe mental illness

Preface

It is only a few decades ago that parents, and other family members, regularly found themselves blamed for the pain and distress of severe mental illness experienced by their children.

Times have moved on - a little. It is rare now for carers to be confronted by psychiatrists, mental health nurses, social workers or other professionals claiming that the family, in all its modern manifestations, is the root cause of schizophrenia, manic depression or other forms of severe mental illness. However, it is still all too common for carers to find themselves excluded from the process of recovery from severe mental illness or to find themselves portrayed as interfering or "difficult" when they raise questions about the services on offer or, more frequently, the absence of these services.

There are now enough official carer frameworks, strategies and pledges in existence to fill a small library. Each attempts to find a central role for the carer in modern mental health service provision. But what is the day-to-day experience of a mental health carer at the beginning of the 21st century?

Who Cares? and the reports that follow it, seek to answer that question. In particular, Who Cares? reports the views of the people who make up the 1.5 million mental health carers in Britain today.

Who Cares? asks how easy is it for a mental health carer to access the support, information and services they need to do their vital, but unheralded job, and it offers some simple recommendations to help government and professionals recognise that recovery from severe mental illness can be made easier when carers are fully involved.

Who Cares? offers of a snapshot of the carer's experience. It also presents a challenge to everyone committed to improving the opportunities for recovery.

We are grateful to our survey partners, the Institute of Psychiatry, Depression Alliance, Manic Depression Fellowship and Carers UK for their support and to The Calouste Gulbenkian Foundation for funding the publication of this report.



Bob Banner, chair, Rethink



Cliff Prior, chief executive, Rethink

Introduction

Rethink regularly carries out social survey research to monitor expert opinion on standards of mental health care. The recent Our Point of View survey, upon which this report is based, asked: are things getting better for the people who use mental health services, their families and friends at the beginning of the 21st Century in Britain?

Survey method

Two versions of the survey were developed, one for service users to report on their experiences and another for carers. Who Cares? - the first in a series of reports exploring the results of Our Point of View - concentrates on the experiences of carers in accessing the support, information and services they need.

Future reports will look at the experiences of service users and the use carers make of the carers' assessment process, designed to address the specific health and social care needs of carers themselves.

Rethink, and its survey partners, sent out approximately 10,000 copies of the nine-page carer questionnaire. We received 1,451 replies. Although the response rate (15 per cent) looks low, it is what we would expect from a survey using indirect mailing techniques, and this is a large survey providing detailed views on carers' experiences. The analysis presented in the report is based on summary statistics and the coding of open-ended questions. The quotations used are selected extracts from the survey.

Who responded to Our Point of View survey?

A summary description of our survey respondents is provided in table one. The findings do not claim to be representative of all carers' views. In fact, because the surveys were sent to people already connected with support organisations, the picture that emerges is almost certainly overly "rosy." The experience of mental health carers who are isolated from formal and informal support networks is likely to be poorer than described here. The picture that emerges of a "typical" carer in our survey is of a woman, usually a mother, in her sixties caring for a man, usually a son in his late thirties, for a period of around 14 years. The son is likely to have a diagnosis of schizophrenia, but for one in four carers, the medical diagnosis of the person they are caring for is not known.

Table one: Demographic information

Gender			
Carers - 1077 female (75%)		Person supported - 980 male (68%)	
Ethnic origin			
Carers - 1307 white british (91%)			
Average age			
Carers - 62 years old		Person supported - 39 years	
Age range			
Carers - 19 - 93		Person supported - 15 to 89	
Region			
South West	188 (13%)	Eastern	194 (14%)
South East	388 (28%)	Midlands	243 (17%)
Greater London	146 (11%)	Northern	195 (14%)
Other (Wales, Scotland and Northern Ireland)		45 (3%)	
Length of time as a carer			
Average - 14 years		Range - less than 1 year to 53 years	
Main diagnosis of the person supported			
Schizophrenia	642 (44%)	Depression	46 (3%)
Manic Depression	136 (9%)	Psychosis	34 (2%)
Schizo-affective	53 (4%)	Personality Disorder	18 (1%)
Other	182 (14%)	Not Known	340 (23%)

Things can only get better?

Paper commitments from government to improving the experience of caring and recognising its central role in recovering a fulfilling and meaningful life from severe mental illness are stacked high, as table two on this page shows. The government has promised to deliver extra funding for mental health services. Mental health sits, alongside heart disease and cancer, as one of just three priority health areas in the government's flagship NHS Plan.

The good news is that, six years after coming into office, improvements are beginning to be felt on the ground.

- 47 per cent of carers say that standards of mental health care in their local area have improved for carers during the past three years
- 49 per cent of carers say that standards of mental health care in their local area have improved for service users during the past three years

“You have to pester to improve conditions”

However, while carers believe that improvements for service users are spread evenly across the country, there is significant regional variation in improvements for carers, with more carers in the Midlands saying that they had experienced improvements (58%) compared to a significantly smaller percentage in London (41%).

Nor should "improvement" be taken to mean that carers are satisfied. Relative to other areas of health care, mental health services have experienced appalling levels of investment and support for decades¹ and there is a long way to go before all carers report improvements or most carers report satisfaction. For instance, fewer than one in five carers (19%) know of respite services in their area that would allow them to take a short break from their caring role. One in three (31%) had not taken a break lasting more than two days in the last 12 months.

“Our main frustration is lack of professional continuity”

“Some GPs are not very helpful, though better than 20 years ago”

Improvements have been noted by carers, but there is still a long way to go

Figure one: Regional variation in England for carer service standards

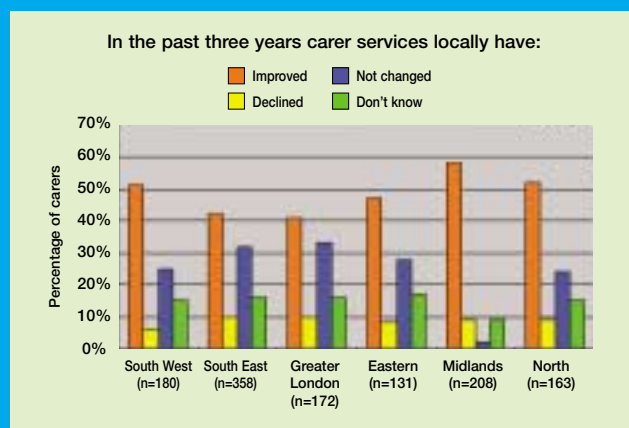


Table two: Government carer initiatives

Source	Target / Principles
Standard 6: National Service Framework for Mental Health (1999) ²	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.
Caring about Carers - National Strategy for Carers (1999) ³	All organisations involved with caring must now focus not just on the client, patient or user - but must include the carer.
Carers and Disabled Children's Act (2000) ⁴	Carers have the right to ask for an assessment of their health and social care needs
The NHS Plan (2000) ⁵	By 2004 700 more staff (carers workers) will be recruited to increase the breaks available for carers, and to strengthen carer support networks.
Labour Party Manifesto (2001) ⁶	"Labour has developed a National Carers' Strategy to provide better support for Britain's six million carers...It comprises £140 million over three years (1999-2002) to help authorities develop more services to give carers a break"
'A Commitment to Carers' Information Leaflet (2001) ⁷	"Everyone in touch with mental health services should have a thorough assessment of their needs and there should be a clear plan for their care and treatment. People with a severe mental illness and/or multiple needs may be cared for under enhanced CPA (Care Programme Approach) and they and their carers should be given a written copy of their care plan"
Developing services for carers and families of people with mental illness (2002) ⁸	- Mental health professionals should have a positive approach to carers, involve them in decision making and recognise them as 'partners' and 'co-experts' - Services should be person-centred, reflecting diversity of carers
Discharge from Hospital (2003) ⁹	- Ensuring that individuals and carers are actively engaged in the planning and delivery of care - Recognise the important role carers play and their own right for assessment and support

Getting involved

Carers, as the name implies, "care." It is an obvious point, but one that has to be made again and again because of continuing professional resistance to carer involvement.

The startling fact is that 92 per cent of carers want contact with a professional, but just 49 per cent say that they are in regular contact all or most of the time.

The myth of the 20th century was that carers – particularly family members – caused severe mental illness or at best made it worse. The emerging myth of the 21st century is that carers are interfering and over-protective, forcing their way in when the person experiencing the severe mental illness wants them kept out.

Yet, less than one in 10 (8 per cent) in the Our Point of View carers survey said that the person they cared for "never" allowed them access to health and social care professionals.

Over half (55 per cent) said that the service users always allowed them contact with the professional while another 37 per cent said that they were sometimes allowed access to the professional by the service user.

The underlying reason then for so few carers being involved with professionals in care planning, discussions about types and dosages of medicines, accommodation or employment is not the relationship between the carer and the service user. The cause must often lie within the relationship between mental health professionals and carers.

For the carer, this relationship can be supportive, nurturing and valued. But, for too many, it is fractious and undervalued. Table three shows that, for carers who are involved by professionals for at least some of the time, one in 10 feel their opinions are rarely or never considered. Although two-thirds feel professionals value and respect their skills, a sizable proportion do not report this as a regular experience.

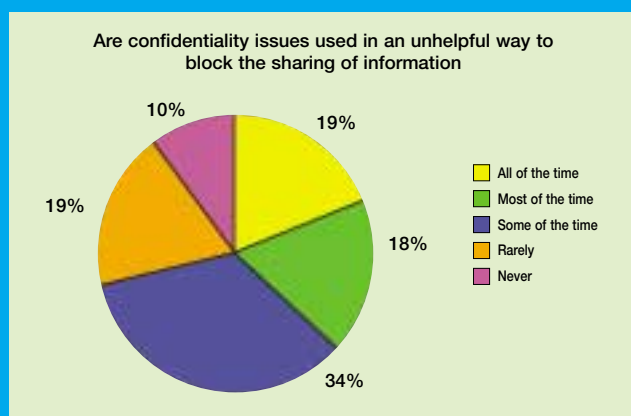
A known barrier to effective carer involvement are "patient confidentiality" rules¹⁰. Despite guidelines strictly defining the limited circumstances when "confidentiality" should be used to block the sharing of information, it remains a serious bone of contention. As shown in figure two, one in three carers (37 per cent) experience the unhelpful use of patient confidentiality regularly. For many carers, this is a priority campaign issue.

Less than 50% of carers get the contact with professionals that they want

Table three: Feeling valued

Carers rating contact with professionals (968 cares – 78%):	Always / Most of the time	Some of the time	Rarely / Never
Feel valued by mental health staff for their skills	67%	24%	9%
Feel mental health staff take their opinions in account	55%	35%	11%

Figure two: Is confidentiality a problem issue for carers?



“We should work towards partnerships in care respecting confidentiality for both user and carer”

“People should not hide behind confidentiality issues”

Getting shunned

Getting the right help at a time when you need it is vital for carers. Being denied access to help is a major frustration.

Despite many carers experiencing improvements over the past three years, 30 per cent of carers still report problems with finding something as simple as a hospital bed when it is needed or the right kind of housing in the community (see table four).

A staggering one in four carers (27 per cent) said that they had been denied access to help during the past three years. Over half of all carers (56 per cent) cited an access related issue as the most frustrating aspect of dealing with mental health services.

Further concerns were raised when we looked at which carers are most likely to be turned away.

It is the carer providing support 24 hours a day seven days a week who is most likely to have been shunned, alongside those carers rating significant affects on their own mental health, physical health, family relationships and jobs of their caring role.

Carers supporting an individual with a diagnosis other than schizophrenia (severe depression, for example) were more likely to have been turned away than people caring for someone with schizophrenia.

“Lack of beds and resources locally means my son doesn't get help until a crisis”

It is worse news again if you are a carer living in London where 39 per cent were turned away when seeking help. Carers in both the Midlands and the North fared best, but even here one in five carers (22 per cent) was shunned.

“No one ever phones back when I make a call requesting help. Usually takes seven or eight calls to get hold of anyone!”

1 in 4 carers are turned away when they seek help from professionals

Table four: Frustrating aspects of the mental health system

Strength of Theme* (n=1451)	"Top" Carer Frustrations
30%	Shortage of adequate service provision locally e.g. in-patient beds, supported residential accommodation, transport in rural areas.
16%	Access to crisis services e.g. difficulty accessing services out of hours, lack of crisis prevention work.
14%	Access to mental health professionals e.g. difficulty getting appointments, answer –machines and calls not returned, not knowing whom to contact.
11%	Quality of mental health care staffing e.g. concern over staff training, inadequate empathy and listening skills, low levels of experience.
10%	Treatment of carers by professionals e.g. not being taken seriously, not being listened to or valued.

* Note: Carers could each provide more than one frustration



“It takes so long to get an appointment, there is no sense of urgency on the part of the professionals”



“I couldn’t have better help and support, everyone should have the same”

Table five: Carers’ experiences of helpful services for people with mental health problems

Strength of Theme	Most useful service provision locally for service users
28%	Rethink services
19%	Community Psychiatric Nurses
13%	Day centres / Drop-ins / Resource centres
12%	Mind services
8%	Crisis teams (inc. home treatment and assertive out-reach)
8%	Housing services

Table six: Seeking help

When you are worried or concerned about the person you support, and need someone to talk to, who do you get in touch with?		
No one available	63	5%
Family members	761	56%
Mental health Professionals	517	38%
Friends / Neighbours / Work Colleagues	396	29%
Staff in voluntary organisations	185	14%
Other carers	68	5%
Church	24	2%

“Staff vary - some very good, others suspicious of family. Constant turnover of staff is unhelpful - why bother to build up relationships with them if they will soon be gone”

1 in 6 carers have no carers services in their area despite government commitments

Getting support

Carers, unsurprisingly, find support from a variety of sources. Quality care and knowing that the person they care for is getting the help they need to lead a fulfilling life is support in itself.

Rethink operates over 400 community services across England and Northern Ireland, with sister charities Hafal operating in Wales and NSF (Scotland) operating in Scotland. These services are, for the most part, non-medical, concentrating on supporting people in gaining quality accommodation, meaningful occupation in day services or moving back into employment. It is significant that these community services, rather than medicalised interventions, rate so highly amongst carers.

For instance, carers reported their role would be easier if you could "take away worry of patient being sent home from hospital with no money" or ensure that there was "proper care in the community - not just dumping someone in flat and hoping that they will care for themselves."

The most useful types of support recognised by carers for service users in their local area are shown in table five.

Amongst medical professionals, Community Psychiatric Nurses, who are often the main point of contact with service users, came highest (19 per cent). The newer services introduced in the last few years as part of the government’s reform programme, such as assertive outreach teams, were also rated by carers as helpful additions.

The government has pledged more resources for carer specific services. Yet a staggering figure of almost one in six carers (17 per cent) report that today there is still no support locally for them.

Things may be about to get better with an extra 700 carer support workers to be recruited by April 2004. However, those already appointed have to make their presence fully felt, with only 5 per cent of carers naming them as most useful.

For services offering support targeted at carers specifically, the most useful were carer support groups (45 per cent), Rethink (17 per cent), CPNs (5 per cent), family workers (5 per cent), and carer education programmes (3 per cent).

Outside agencies, whether the statutory professionals or workers in the voluntary sector, ignore the role of existing and peer-to-peer support networks of family, friends and other carers at their peril. While the 45 per cent of carers rating carer support groups as most useful may be citing a service provided by the voluntary or statutory sectors, it is the peer-to-peer support found there that matters.

This view is reinforced when carers speak about where they seek help when they want someone to talk to about the person they care for, as shown in table six. Over half (56 per cent) turn toward the family.

Getting information

Effective communication and information sharing, or the lack of it, are common themes that emerge from this research.

One in four carers (25 per cent) feel that they don't have any information to help them.

Among those that do have some information, one in three do not have enough. These carers want to know a lot more about medication, specific mental health problems, new treatments, local service provision and coping strategies. These are the same topic areas that carers highlighted in our Silent Partners research report in 1995¹¹ - why are so many carers still being kept in the dark?

As with other issues, we have found significant regional variations in carers' reporting on information provision locally. As shown in table seven, carers in the Midlands again fared best while carers in London found it hardest to get information.

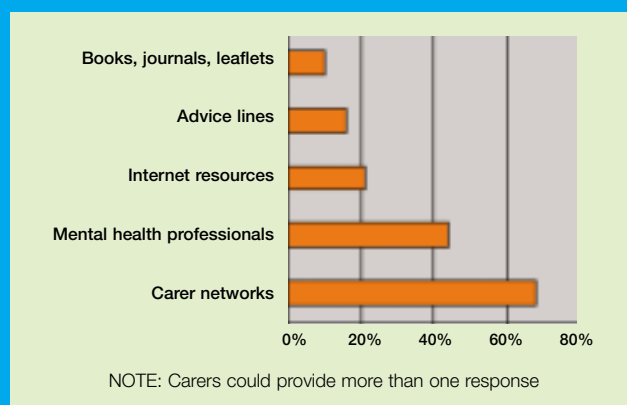
Most carers rely on carer support networks for information, though as increasing numbers have access to the internet - 54% of carers in this survey - there may be greater access to information. However, access to information is not the only issue, carers also report needing support to make sense of these materials as well.

1 in 4 carers don't feel they have enough information to help them

Table seven: Reported regional variations for accessing information

Do you have sufficient information?	
Average	63%
South West	66%
South east	63%
Greater London	56%
Eastern	57%
Midlands	72%
North	63%

Figure three: Who is delivering information to carers?



“Most important factor, initially is that facts are needed about the illness. I learnt through research and trial and error. The more carers understand the better it is for user and carer”

“Professionals must stop pushing carers out from information involving the patient. They need to be open, respectful and able to discuss the problems taking place. This situation is no better than years ago”

1. Wanless D (2001) Securing our future health: Taking a long term view. London: HMSO.
2. Department of Health (1999) National Service Framework for Mental Health. London: HMSO.
3. Department of Health (1999) Caring about carers. A national strategy for carers. London: HMSO.
4. Carers and Disabled Children's Act 2000
5. Department of Health (2000) The NHS Plan : a plan for investment, a plan for reform. London: HMSO.
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8. Department of Health (2002) Developing services for carers and families of people with mental illness. London: HMSO.
9. Department of Health (2003) Discharge from hospital: pathway, process and practice. London: HMSO.
10. Arksey et al (2002) Literature review report: Services to support carers of people with mental health problems. University of York: NHS Centre for Reviews and Dissemination.
11. Hogman G, Pearson G (1995) Silent Partners: The needs and experiences of people who provide informal care to people with severe mental illness. London: Rethink Publication.

Recommendations

Getting the message

While this report, and the ones that follow, are based on a large and meaningful sample of carers who can be reached by the networks of the partner organisations, there are many isolated carers who are not in touch with organisations. Their experiences are likely to be poorer than those reported here.

Carers want to be involved, want to be valued and want to secure the best care as early as possible for the person they care for.

Too often they are left out of the loop by professionals, they feel under-valued and are left to fall back on family and friends for support.

Things are getting better for many, but quality services, easily accessible round-the-clock support and open access to professionals are still at a premium.

Reforms still have some way to go to iron out significant geographical variations in services that are too often offered in ways that exclude the full-time carer with the greatest need.

Carers should:

- Be recognised and listened to as a partner in providing care
- Be valued
- Be treated with courtesy and respect
- Be able to talk to a mental health or social care professional on request
- Receive information as early as possible
- Receive prompt and positive responses to requests for help
- Be able to get immediate help in a crisis
- Have their own needs assessed and met
- Be able to have breaks from caring
- Be given help in communicating with staff, when needed, for example through an advocate, interpreter or signer.
- Be given an explanation of the mental health problem affecting the person they care for
- Be told what treatments the person is receiving, what other treatments are available, how they work and the potential side-effects
- Be given information about what support will be provided when the carer is no longer able to provide care

We are grateful to all the carers who took the time and trouble to complete the Our Point of View survey. Without their efforts, this research would not have been possible.

We are also grateful to our survey partners the Institute of Psychiatry, Depression Alliance, Manic Depression Fellowship and Carers UK for their support, and to The Calouste Gulbenkian Foundation for funding the publication of this report.

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Rethink publishes an extensive range of publications for carers including *Caring & Coping*, a practical book designed to help carers of people with severe mental illness and *A Commitment to Carers*, a leaflet providing basic information on help available to carers.

To order copies or to find out more about Rethink's publications call 0845 456 0455 or log on to www.rethink.org.

If you feel it is important that Rethink continues to speak out about the issues dealt with in this report why not become a Rethink member and help us speak out for everyone affected by severe mental illness. Call 0845 456 0455 or join online at www.rethink.org/membership.

We are also pleased to announce a new mental health website from the Institute of Psychiatry, South London and Maudsley NHS Trust and Rethink to provide helpful evidence-based information for carers of people with mental illness. www.mentalhealthcare.org.uk

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