Under Pressure

The impact of caring on people supporting family members or friends with mental health problems

Rethink Mental Illness.

Legacy publication

rethink
severe mental illness

Table one: Government's commitments to carers

1990: NHS and Community Care Act
Framework for the development of modern mental health services, including recognition that public bodies should be doing more to support carers.

1995: Carers (Recognition and Services) Act
Carers, who provide care on a substantial and regular basis, have the right to request an assessment of their ability and willingness to cope with their caring role.

1999: National Service Framework for Mental Health, Standard 6
Health and social services should assess the needs of carers who provide regular and substantial support to those with severe mental illness, and provide care to meet their needs.

1999: Caring about Carers – National Strategy for Carers
Government commitment to carers including policy packages and funding for carer specific information, support and care.

2000: Carers and Disabled Children's Act
Legislation empowering local councils to provide specific services to carers following an assessment of their health and social care needs.

2000: The NHS Plan
By 2004, 700 more carer workers recruited to increase the breaks available to carers, and to strengthen carer support networks.

2002: Developing Services for Carers
Guide for developing support services for mental health carers. Services should be person centred, positive and reflect diversity of carers who are viewed as co-experts.

2003: Discharge from Hospital
Engagement and active participation of individuals and their carers as equal partners is central to the delivery of care and in the planning of a successful discharge.

Preface

Our recent report, *Who Cares?* asked how easy – or difficult – is it to access the support, information and services needed to be a mental health carer in 21st century Britain. It found that there are substantial barriers that not only prevent many people being as effective as they would want to be, but add to the considerable challenge of being a carer. However alongside carer difficulties we also found that overall, many carers were recognising improvements in mental health care provision on the ground in their localities.

Under Pressure poses a new set of questions – what impact does caring have on the individual carer and what kind of relationships with mental health services most benefit carers? It asked carers similar questions to those posed in 1994 with our *Silent Partners* research, and although the answers are complex, consistent with the nature of caring relationships, a few simple truths stand out:

- Involved and supported carers have a better experience and are more effective carers than those who are uninvolved and without access to support and information
- Even those carers reporting positive experiences of mental health services do face lasting adverse affects on their own mental health, physical health, finances, family relationships, careers and leisure time
- The most important changes that carers want to help them are improved access to support and care for mental health service users and increased recognition of carer involvement
- Carers have a legal right to have their own needs assessed but few make use of this right and for those who do, many do not receive any extra help as a result

Mental health carers, numbering approximately 1.5 million, are recognised now in a way that they were not 20 years ago. More carers than ever before are involved not just in one-to-one care but also in the planning of mental health services.

On paper, carers have never had it so good.

And yet the reality of caring today is to see a deterioration in your own mental and physical health, reduced finances and career prospects, strained family relationships and lost leisure. There are regional variations in the availability of information, help and support. Too many carers find the present legal right to an assessment of their needs a sham because identified needs go unmet.

Pockets of good practice for supporting carers are emerging but the challenge is to see these vital supports and services extended to all.

We are grateful to our survey partners: Carers UK, the Institute of Psychiatry, Depression Alliance and Manic Depression Fellowship for their support. Like our *Who Cares?* report, *Under Pressure* offers a snapshot of the carer's experience. It also presents a challenge to everyone committed to improving opportunities for recovery.

Robert Banner, Chair, Rethink

Cliff Prior, Chief Executive, Rethink

Introduction

When does a friend or a mother, father, brother, sister, son, daughter, wife, husband or partner become a mental health carer? 'Carer' is a much fought-over term. Many carers object to this label because it implies that somehow they did not 'care' before the person they support became ill or that it unhelpfully 'professionalises' their relationship. Others do not recognise the carer role at all and identify solely with their relationship roles. Still others complain that health and social service staff waste time focusing on the 'well' carer when they should be focusing on the 'ill' service user.

The relationship between the person using mental health services and the carer is unique and complex. It is rich and valuable but can also be tense and fraught. Whatever it is, it cannot be ignored in any process of recovery toward a full and meaningful life for someone living with a severe mental illness.

Support for carers

We know that supporting people with severe mental illness is demanding and impacts on carers own health and well being (Rethink, 1995; Princess Royal Trust for Carers 2002; Szmukler et al 2003). We also know that there is lack of clear evidence to support any one specific intervention to reduce 'carers' burden' (Arksey et al 2002) particularly when specific groups of carers are the focus of study e.g. black and minority ethnic carers, young carers, carers of people with dual diagnosis. But what do mental health carers say makes a difference?

This report is based on findings from a large national survey of carers' views carried out between November 2002 and February 2003. *Under Pressure* focuses on two principle questions:

- How has the mechanism introduced to provide carers with a gateway to statutory support – the carers' assessment – been received?
- What helps carers to support their own health and well being?

Our Survey Respondents

Table two describes our sample, most of whom were reached through our membership networks and those of our partners, and therefore this is not representative of mental health carers in general. The voices of many isolated and unsupported carers will not be heard here but the experiences of 1,451 people are shared to describe how well-connected carers on the ground are beginning to experience government commitments to 'support carers'. The experiences described here may well be better than those experienced by the 'average' carer, though people who join health charities are themselves often caring for people with more severe health difficulties.

Table two: Sample characteristics

Gender		
Carer - 1077 female (75%)	Person supported – 980 male (68%)	
Ethnic Origin		
Carers – 1307 White British (91%)		
Average age		
Carers – 62 years	Person supported – 39 years	
Length of time as carer		
Average – 14 years		
Range – less than 1 year to 53 years		
Main diagnosis of person supported		
Schizophrenia	642	(44%)
Manic Depression	136	(9%)
Schizo-affective	53	(4%)
Depression	46	(3%)
Psychosis	34	(2%)
Personality Disorder	18	(1%)
Other	182	(14%)
Not known	340	(23%)
Relationship of the person carer supports		
Family	1377- (95%): sons (54%), daughters (19%)	
Friend	38 (3%)	
Other	24 (2%)	
Hours per week providing support and care		
Over 50 hours	399	(29%)
11-20 hours	219	(16%)
21-50 hours	277	(20%)
1-10 hours	460	(34%)
(570 carers - 40% live with the person they support)		

The adverse impact of caring roles on carers themselves

Many carers do not recognise their own needs for support. Too many become worn down by their role before any support is offered. Too often carers are taken for granted, ignored or deliberately shut out by professionals who see them as part of the problem rather than vital to the solution. Not enough carers are routinely referred by staff to carers' support groups who can assist and help them.

The impact of caring can be huge. Over these next two pages we examine carers' own views of the consequences of caring for their health and lives.

Adverse impact of caring roles on health are very common

The caring role adversely affects the health of nine out of 10 carers to some extent. This compares to 71 per cent in our *Silent Partners* research, but is the same proportion reported among mental health carers in research by Princess Royal Trust for Carers (2002). For 41 per cent of carers both their mental and physical health has been moderately or significantly affected by supporting a friend or relative with mental health problems. Among all mental health carers depression, worry and sleeplessness are reported as commonplace. Where problems are most severe for the service user, the impact on the carer is the greatest.

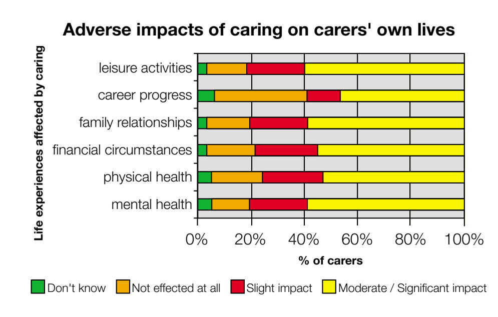

Figure one: The human costs of caring

Caring significantly affects a person's whole life

The costs of caring are far reaching as shown in figure one. 60% of carers find that their ability to have a social life outside the home is significantly or moderately affected. Family relationships are seriously affected in three out of every five carer households. 19% of carers report a moderate to significant impact on all of our six health and social care concerns – mental health, physical health, financial circumstances, family, career, leisure. Carers also report that their support role affects other important aspects of their lives, including their mobility and freedom, being able to go away on holiday, move house and sustain a social life beyond the home.

> "It takes over your whole life – everything changes"
> (Carer from Wales)
>
> "Ability to focus thoughts on things other than caring on a daily basis is very difficult indeed"
> (Carer from Birmingham)

> "If our son was properly looked after we would have few needs. As it is we have the ever present worry about him which is debilitating and causes stress related conditions"
> (Carer from Buckinghamshire)

What would make the most difference to carers? We asked carers to tell us about the changes they wanted to see in the next five years. 21% voted for greater access to help and support for service users, 20% wanted more widespread consultation with carers, 17% wanted more support for service users from mental health professionals and 17% wanted better choices in accommodation for service users. As several studies have shown, alongside specific carer services and increased levels of carer involvement, people want to see their friend or relative recover a decent quality of life and good mental health – in the process relieving them of some or all of the caring role.

Caring around the clock takes its toll

In our survey 29% provide care for over 50 hours per week which compares to 11% in the national profile of all carers (ONS, 2002). All types of carers providing the largest support role commitments report a greater number of adverse health and social impacts resulting from their caring role than those who are less involved, though the '24 hour a day worry' is rarely monitored. In our study we do see a link between reported caring commitment and adverse impacts on the carer. Our research shows that one in four people providing support for over 50 hours per week report a moderate to significant impact on all six concerns listed in figure one compared to one in ten of carers providing one to five hours of support each week.

Easing the pressure with experience and information

Expert experience and information are key resources for carers. Those with most experience in the caring role – i.e. those who have provided support for longer – and those with the most information about their role and the diagnosis of the person they support report fewer adverse effects than new carers and those with little information (see figure two). We also note that carers with most mental health needs themselves are being pro-active in seeking support. For example, these carers are more likely to be involved in carer support networks, and are more likely to be connected to the internet.

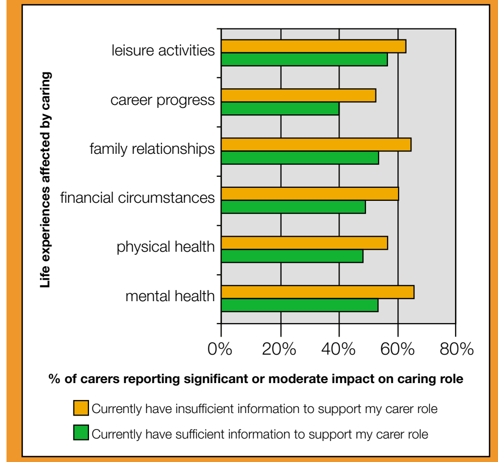

Figure two: Being informed does help

Professionals' attitudes make a difference

Does involvement with mental health professionals ease the carer's role? As shown in figure three, where staff value and respect carer skills and the help they provide to service users, the impact on carers' mental health is significantly reduced. The same trend was also observed for impacts on physical health and career progress.

We also asked carers if staff took their opinions into account. Again, carers who felt ignored by professionals experienced worse adverse effects across all six of our health and social concerns. For example, when staff consider carer views 'all of the time' 47% of carers report a moderate to significant impact on physical health compared to 62% of carers whose views are 'never' considered.

> "I find it very frustrating, not being treated as a member of support team by some CPNs – carers need to feel more valued and involved"
> (Carer from Hampshire)
>
> "There are plenty of consultation exercises, but help for individual carers is not properly tackled"
> (Carer from South London)

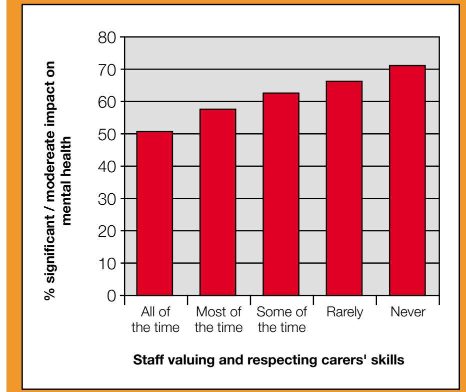

Figure three: Adverse impacts of caring on carer's mental health

Having a choice

50% of carers feel they never have any choice about whether they continue to provide help and support. We also asked if people felt health and social care services would be able to provide support and care if they were no longer able to be involved, 60%t were not sure and 20% were certain this would not be possible.

A lack of choice over caring responsibilities is related to increased levels of mental health problems among carers, and also financial pressures. Those carers who always have a choice over caring roles report 46% significant or moderate impact on their mental health compared to 63% of carers who report they never have any choice.

> "I feel professionals automatically believe that as I am the parent I'll do it anyway"
> (Carer from Liverpool)

Summary: Adverse impacts of caring

The findings on these two pages are consistent with research carried out elsewhere. They point to some simple truths which many professionals are just beginning to grasp – involved, supported carers, able to access the right information and support networks experience fewer adverse effects and are more effective carers than those kept in the dark and isolated. However, even for those with the best experiences, there can still be real and lasting effects.

What helps carers?

- Timely information
- Specific support services for carers
- Being involved and consulted by health and social care professionals
- Contact with professionals
- Choice and consultation

What hinders carers?

- Lack of information
- Insufficient support
- Exclusion by professionals
- Caring in isolation
- No choices over involvement, level of in-put, services being delivered to service user

Key findings

62% of carers know that they can ask for a carers assessment but only one in four carers had been assessed either by themselves or someone else e.g. social worker.

Whether a carer receives an assessment is still a regional lottery with just 12% of carers in Eastern region and 19% in London having carers assessment compared to about 25% in the other regions (The North, The Midlands, South West and South East).

One in three carers said that after their carers assessment none of the health and social care needs identified were being addressed. Two in five of the carers assessments within our sample were carried out over 12 months ago and the reported picture is the same, 35% have received no help for identified needs.

Experience of carer assessments

Carers have a right to ask for their own needs to be recognised by a local authority through a Carers Assessment to identify carer's needs and make recommendations on how these can be supported and 'met'. The take up of these assessments in our survey is low. A selection of quotations illustrating common points of view and experiences are listed below.

Positive experience: Assessments as helpful

'Makes me feel someone cares about what I have to do each day. Not so alone.'

(Woman aged 55 from Surrey, caring for her husband diagnosed with manic depression)

Progressive view point: Assessments are OK as long as they lead to change

'A great idea, I would like some support'

(Mother from Kent, caring for her son aged 41 with manic depression).

"Would like one, but what can they do to change things?'

(Mother from Leicester caring for her son aged 24 with schizophrenia)

Pessimistic view point: Assessments are window dressing and required services are largely unavailable

'Too late. 20 years too late. I have cancer. Son at home 3 days a week. Husband has had a stroke. A lot of hot air about help. It never happens'

(Mother from Worcestershire caring for her son aged 41)

'I believe that carers assessment are not much more than a paper exercise. I have not met any carers who have been advantaged by one'

(Father from Hampshire, caring for son aged 42 with schizophrenia)

Negative viewpoint: Assessments are unnecessary

'Do not want assessment, would find it intrusive. If relatives had proper services and facilities and places to live, our needs would be met.'

(Mother from Lancashire, supports son aged 33)

Practical view point: the process needs to be carer led and lead to change

'I have been offered a carers assessment but will wait until I have a practical problem which I can not cope with'

(Mother from Hampshire, caring for son aged 24 with paranoid schizophrenia)

'Would have to be assessed by same person who is so restrictive of daughter - would not trust this person to see my point of view. If I could be assessed by a genuinely neutral person I would go for it'

(Mother from South London, carer for daughter aged 37 with schizophrenia)

Negative experience: Assessments are unhelpful

'We filled out our own form. Taken by CPN and returned without comment or information added. Pointless, upsetting and achieved nothing'

(Mother from East Sussex, provides care for son aged 31)

The problem with assessments

Most carers (89%) have significant health needs of their own. Yet only one in five have had a carers assessment. Of this group, only half have had their identified needs met. It is true that many carers do not see themselves as being in need and so may don't seek it out. However, many of those who do, have a negative experience and end up with no more help or support. These experiences are similar to those described in the recent Missed Opportunities research carried out by Carers UK (2003).

Under the Carers and Disabled Children's Act (2000) a carer may request a local authority to assess their needs at the same time as the person they care for is assessed. Under this Act, however, there is no duty on local authorities to provide services for carers. A carer may hold a piece of official paper confirming that they are experiencing real adverse effects from their caring role that need help and support. But that piece of paper is far from being a passport to support.

It is not enough that carers have a right to an assessment, they must also have the right to receive the support they need. Providers must ring fence resources so that recommendations to address identified carers' needs can be financed. We welcome the introduction of carers' assessments, and there are carers who have found the process of 'being assessed' helpful and positive in terms of identifying and talking through their own needs. So many more carers would benefit, however, if some of the mountain of 'unmet need' was also addressed through this supportive process.

References

For more detailed summary of these references please visit www.rethink.org/research. Research updates for carers can also be found at www.mentalhealthcarers.org.uk

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.

Carers UK (2003) Missed Opportunities. The impact of new rights for carers www.carersonline.org.uk

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.

Keeley B, Clarke M (2002) Carers Speak Out Project report on findings and recommendations. London, Princess Royal Trust for Carers Publication.

Office of National Statistics (2002) Carers 2000 General Household Survey. London: HMSO.

Pinfold V, Corry P (2003) Who Cares? The experiences of mental health carers assessing services and information. London: Rethink Publication.

Szmukler G et al (2003) An exploratory randomised controlled trail of a support programme for cares of patients with a Psychiatry. Social Psychiatry and Psychiatric Epidemiology, 38: 411-418.

Key findings (cont)

One in five carers in our survey had a carers assessment (310 people) but has it made a difference? Over half of those assessed (57%), have no care plan, 15% don't feel they need a care plan and only 28% actually have a care plan addressing their needs.

A few carers (18%) provided views on the carers' assessment process. 58% felt that it was positive and were willing to be assessed, 23% felt the process was a waste of time believing nothing will change as a result of an assessment, while 9% felt that it was not relevant for them – many stating they had needed help in the past when none was available but not now.

You are most likely to receive an assessment, if you live with the service user, are involved in their care planning process, experience moderate or significant mental health needs yourself and feel that services in your local area are improving.

Recommendations

This report has shown that carers who receive timely information, are in contact with professionals, feel involved, valued and respected and have their own needs assessed and met experience fewer and less severe adverse effects to their own mental and physical health, family relationships, finances and careers and have more time for their own leisure pursuits.

Access to Information

- Receive information as early as possible
- Have regular access to updated sources of information
- Receive information in a language of their choice
- Have the opportunity to ask professionals questions about the information they have received
- Be given information about what support will be provided when they are no longer able to provide care

Support for Carers

- Be able to get immediate help in a crisis
- Have their own needs assessed and met
- Have unmet needs audited by mental health and social care professionals
- Have access to a local support network for carers
- Be given help in communicating with staff, when needed, for example through an advocate, interpreter or signer
- Receive prompt and positive responses to requests for help
- Be able to attend carers education courses

Carers must exercise their legal right to an assessment of their own health and care needs and have identified needs met with appropriate support and services. This also means that more resources at a local level must be allocated to providing support to carers.

Involvement

- Carers' rights protected under the mental health act
- Increased recognition of carer role by GP's and mental health professionals
- Where appropriate 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
- Where appropriate be involved in care planning
- Be involved in service development at local and national levels

Professional Contact

- Be recognised and listened to as a partner in providing care
- Be valued by mental health professionals
- Be treated with courtesy and respect
- Be able to talk to a mental health or social care professional on request

Choice

- For there to be realistic alternatives if carers can not provide care
- Be able to have breaks from caring
- Have access to a range of information to make informed choices with service users on care and treatment options

Rethink service information

Rethink has been working with carers for over 30 years. In that time the organisation has undertaken research into carers, provided mutual support groups (125 currently) and provided services such as respite care, advocacy, carer support, education and training. Rethink currently operates over 50 carer support / education services, including specific service provision for carers from minority ethnic groups. A conservative estimate would be that at least 50,000 different carers have been meaningfully involved with the organisation at some point in our history. To find out how to access a local carers group in your area, please contact Rethink on 0845 456 0455 or e-mail info@rethink.org

Carers' needs change over time and a process of assessment, provision and review is required so that these needs can be met. Rethink is campaigning constantly to ensure Carers remain on commissioners' agendas and that they are equal partners within the mental health system.

For more information on Rethink and the services and publications it offers to carers, including a new book called Caring and Coping and a leaflet 'Commitment to Carers', please do visit:

- www.rethinkcarers.org, a virtual, web-based community and information resource for carers
- www.mentalhealthcare.org.uk, a research-based website for carers developed by the Institute of Psychiatry, South London and Maudsley NHS Trust and Rethink
- www.rethink.org, a one-stop guide with over 2,000 pages of information on severe mental illness, Rethink, its services and campaigns
- www.rethink.org/publications for all the latest information on Rethink publications

Or contact us at Rethink,
28 Castle Street, Kingston Upon Thames, Surrey KT1 1SS
Phone 0845 456 0455
Fax 020 8547 3862
email info@rethink.org

rethink
severe mental illness

Rethink is the operating name of National Schizophrenia Fellowship, a company limited by guarantee. Registered in England no 12279770. Registered Charity No 271028. Registered office: 28 Castle Street, Kingston Upon Thames KT1 1SS.

Report authors: Vanessa Pinfold and Paul Corry, November 2003

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

Publication of this report has been supported by Lundbeck Ltd in partnership with Rethink. Lundbeck's mission is to improve the quality of life of those who suffer from psychiatric and neurological illness and believes this is best achieved through investment in knowledge, research, education and holistic attitudes to patient care.