



Kirsty Matthews

Supporting carers

Mental health carers' assessments in policy and practice

Key Points

- The Care Act (2014) came into force in April 2015, with part of its remit to recognise the role and importance of carers, and to give carers greater legislative power.
- Carers' assessments are a key feature of this act. They are a duty placed on local authorities to offer carers an assessment of their needs, in order to identify potential, additional support.
- The Carers UK report *State of Caring 2016* presents a bleak picture of the implementation of the Care Act (2014), arguing that its promises have not been realised for all.
- 1.5 million carers in the UK look after an individual with mental ill health (Carers Trust, 2013). This can have an impact on their ability to work, socialise and live their life to the full.
- Mental health carers face significant challenges to access carers' assessments and appropriate support. Barriers can include information sharing, stigma, terminology and the quality of delivery.
- Practitioners who deliver mental health carers' assessments can be under pressure to deliver certain quantities of assessments, which may restrict their ability to focus on quality of support.
- There are great strides to be made in statutory processes to enable mental health carers to be adequately supported, and care practitioners to fulfil their potential.
- Further research is needed to understand the inequality experienced by mental health carers in terms of assessments, to share good practice and to make recommendations for improvement.

Introduction

The Care Act 2014 was implemented in April 2015, strengthening the rights of carers and recognising their importance in society. A key feature of this act was the duty for local authorities to provide carers with assessments, to identify the support they need and to consider carers' physical and emotional wellbeing. Carers' assessments thus are a mechanism to ensure carers are supported in their roles, and are able to access additional help to lead their day-to-day lives fully.

Carers UK (2016b) *State of Caring 2016* explores the current experiences of carers, arguing that policy has not been translated into practice. Carers UK states that implementation of the Care Act (2014) has been varied. It found that only 31% of the carers they surveyed had had a carer's assessment in the past year. Carers who support an individual with a mental health condition fared worse, with only 48% of these carers having received an assessment within six months after it was offered or requested (Carers UK, 2016b). This compares to 55% of carers who look after older people.

Currently 1.5 million people care for someone with a mental health problem in the UK (Carers Trust, 2013). These carers may have to cope with unpredictable situations, often for long hours and with little assistance (Carers Trust, 2015). They may need substantial support from statutory bodies.

This briefing paper provides a summary of the policy and legislation relating to mental health carers' assessments in England, and the results of exploratory research. We used informal interviews to elicit the opinions of a number of individuals from NHS trusts, local authorities, and carers themselves. An example has also been included to exemplify areas of innovative support. The main recommendation of this report is the need for further research to fill the gap in literature that exists, in order to highlight the current barriers to effective implementation of the Care Act and to champion the need for carers to be adequately supported by statutory bodies.

Carers

A carer is defined as 'someone who helps another person, usually a relative or friend, in their day-to-day life' (NHS Choices, 2015b). Simply put, carers give up their time to help an individual in need without payment. Caring will become an aspect of many of our lives, especially with an increasingly elderly population.

Caring can be both a rewarding and fulfilling experience, although concomitantly it does present particular challenges. Indeed, the personal costs can be significant. Caring can affect your ability to work, socialise, look after yourself and live fully day-to-day. Caring can put strain on an individual's finances, especially if the carer has to give up paid employment. It can also lead to social isolation (Carers UK, 2015). Some 83% of carers felt that caring has a negative impact on their physical health, and 87% that it undermines their mental health (Age UK *et al.*, 2012).

Carers contribute a significant amount to UK society. Without carers, the NHS and social care services would be under considerably greater pressure to sustain their services. Carers UK (2016b) has calculated that the contribution of carers is worth £132 billion, almost equivalent to the annual spend on UK health care.

1.5 million people care for an individual with mental ill health within the UK (Carers Trust, 2013). Mental health carers face particular challenges, for example with confidentiality and sharing information with professionals, and the unpredictability and the stigma associated with mental health (healthtalk.org, 2013).

National carers' organisations, such as Carers UK and Carers Trust, have a powerful vision for carers. They want them to 'count', be properly valued, have the choice to continue caring, and be able to live their lives fully while caring (Carers UK 2016a, Carers Trust n.d.).

The Legal Context

The rights of carers have been recognised in legislation. The Care Act (2014) specifically refers to the rights of adult carers (over 18 year olds who look after another adult).

It was preceded by three previous acts:

- The Carers (Recognition and Services) Act 1995;
- The Carers and Disabled Children Act 2000;
- The Carers (Equal Opportunities) Act 2004.

The right to assessment for young carers and adults caring for a disabled child is covered by the Children and Families Act (2014). This report specifically refers to the Care Act (2014).

The Care Act (2014) makes specific consideration for carers in terms of support, information and assessment, regardless of a carer's financial situation (Carers UK, 2014). Its defining feature was that, for the first time, carers were given legal rights to receive services (Carers UK, 2014). This differs from previous acts as carers no longer have to care for a specified amount of time, and they are not required to ask for an assessment (Carers UK, 2014). Over time and through the progression of successive legislation, a paradigm shift has resulted in carers no longer being seen as simply unpaid workers providing care, but as individuals with a right to be supported themselves (Clements, 2012).

The Care Act (2014) states that local authorities have a duty to collaborate with relevant partners, including the NHS, to meet these new requirements. Under Section 75 of the Act, local authorities and NHS bodies can work in partnership with one another, and thus the responsibility for some carers' assessments can be delegated to NHS mental health trusts. Local authorities may also commission the delivery of carers' assessments through third sector and private organisations.

Carers Trust (2016) *Care Act for Carers: One Year On*, reports on the impact of the Care Act after its implementation. Resolutely, Carers Trust states that carers have yet to feel the difference. This is confirmed by Carers UK (2016b), whose *State of Caring 2016* report commented on the 'emerging landscape' after the change in law, and stated that the 'spirit' of the Care Act had not been translated into reality (pg.5).

Carers' assessments

The Care Act (2014) mandates local authorities to consider support that a carer may need, through a carer's assessment. A carer has a right to an assessment if the local authority suspects a carer may be in need of support or a carer requests one.

Carers' assessments should cover whether a carer is able and willing to care, the outcomes a carer wishes to achieve in their day-to-day life, and whether any support can be given in response to these (Care Act, 2014). Discussion should also centre on the willingness of an individual to continue caring, rather than it being naturally assumed. The needs of the family should also be considered.

The assessment can take many forms, from a face to face interview to a self-assessment form. Sometimes joint assessments take place, where the carer and the individual who is cared for are assessed simultaneously.

It must be stated that a carer's assessment is not a financial assessment, but instead aims to provide extra support for carers. Local authorities usually do not charge for support given to carers, however, if they choose to do so a further financial assessment must take place (NHS Choices, 2015b).

Support resulting from an assessment can come in many forms, for example advice and information, money or respite.

The Triangle of Care

The Triangle of Care is an initiative set up by the Carers Trust to emphasise the importance of carers in making decisions and being involved with a service user's care (Carers Trust, 2016). It is a 'therapeutic alliance', whereby service users, professionals and carers work together to maximise wellbeing and recovery (Carers Trust, 2013, pg.3). Carers have frequently lamented the lack of consideration of their

views in informing decisions about the person they care for. The Triangle of Care advocates carers as an 'active partner' in care, reducing fragmentation and facilitating communication (see Figure 1, Carers Trust, 2013). The Triangle of Care scheme supports mental health services to achieve the standards as described in Figure 2 below, and awards gold stars to recognise an organisation's commitment to the scheme.

The Triangle of Care

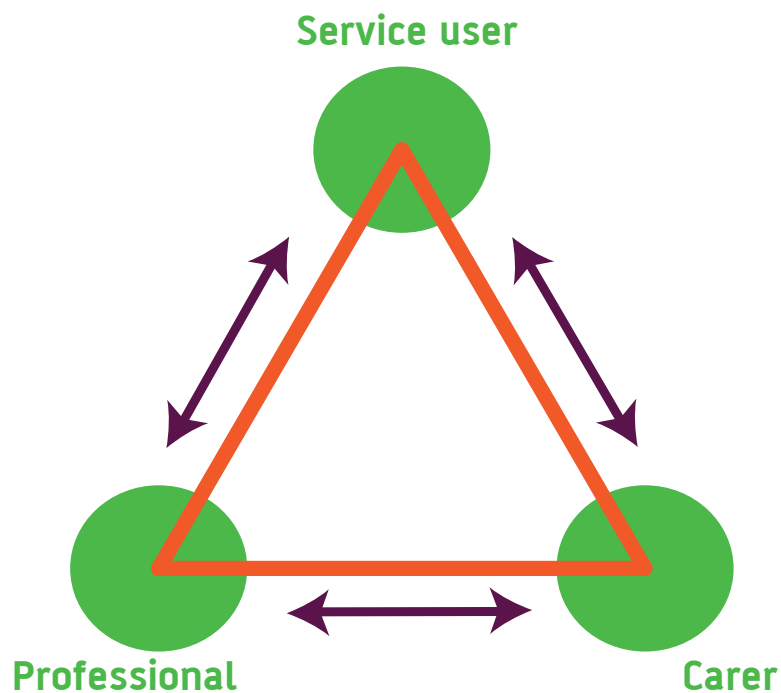


Figure 1, adapted from Carers Trust (2013)

The six key standards are as follows:

1. Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
2. Staff are 'carer aware' and trained in carer engagement strategies.
3. Policy and practice protocols re: confidentiality and sharing information are in place.
4. Defined post(s) responsible for carers are in place.
5. A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
6. A range of carer support services is available.

Figure 2, adapted from Carers Trust (2013) pg. 3

Carers' assessments in practice

Lived experience

The language of carers' assessments

The legal nomenclature of 'carers' assessments' can be extremely daunting to carers, who may feel that they are being assessed financially, or on their ability to care properly. These fears often have to be allayed by practitioners before a carer is willing to partake in one. Nearly all of the people we engaged during our research commented on this aspect of a carer's assessment as a challenge to overcome.

Not only is the term 'assessment' off-putting to some, but also the term 'carer'. Many individuals may not identify themselves as carers, and simply see themselves as a 'parent', 'friend' or 'sibling'. Again, a conversation is needed from a practitioner to broach this topic, and help individuals to come to terms with the title. While it may not be necessary for individuals to identify as a carer, it is important for them to have an awareness of the support that they are entitled to as a result of their role in assisting another individual. And as carers often focus on the needs of the person they care for, they also may need additional assistance in expressing their own needs and realising that professionals may be able to help alleviate some of their stress.

The quality of communication from a care practitioner to a carer is essential when translating policy into practice. A care practitioner is defined for the purpose of this report as any professional delivering a carers' assessment. While the term 'carers' assessment' has an important legal meaning, it need not be used initially when speaking to a carer. A good relationship needs to be built between practitioner and carer, and a conversation needs to be started regarding what help is available to them. This is advocated by Stephen Rabbitts, the Carers Operational Lead for the South Essex Partnership NHS Foundation Trust. In his Carers' Awareness Staff Training Course, he asserts that delivery is paramount, and the need to engage with carers in a relatable manner is crucial.

Easy access to information for carers is also essential, as the health and social care landscape can be difficult to navigate. Good quality information leaflets and guides are useful as they allow carers to digest information at their own pace. To facilitate this, the North Essex Partnership University NHS Foundation Trust have developed a public microsite for carers, and a carers' handbook. Having a resource that signposts to appropriate people and services, which can be read time and time again, is of great benefit.

Fragmentation and Information Sharing

Historical views and perceptions regarding the role of the family in contributing to mental illness, and regimented data protection laws regarding information sharing introduce extra difficulties into the lives of mental health carers. Consent and professional codes of conduct may prevent certain information being shared with a carer. This can lead to a carer having insufficient knowledge of the condition of the person they care for, which may restrict the level of support they can give and seek from external organisations. Equally, mental health carers may struggle to communicate issues with professionals themselves regarding the individual they care for, if they wish to raise concerns or present a different perspective.

Whilst it is important to recognise that not all relationships between carers and the cared for are constructive, information sharing in many cases can be beneficial. The close relationships that exist between these people mean that a carer often knows the service user extremely well and can be of assistance to professionals. When information is shared, carers can provide more effective support (Royal College of Psychiatrists, n.d.).

An example of good practice in data sharing can be seen at the North Essex Partnership University NHS Foundation Trust (NEP). NEP have created 'common sense confidentiality guidance' and an accompanying decision-making flowchart for their staff. This aids professionals in making the right decision in

sharing information so that carers and the people they care for benefit, and all appropriate laws are adhered to.

Stigma also plays a part in the inequality of service provided to mental health carers (Carers UK, 2016b). The ‘invisibility’ of mental illness may mean that carers are overlooked, with their role as carers being unidentified. This acts as a barrier to services, leaving mental health carers inadequately supported by professional services, which can have damaging consequences.

Onward support from a carer’s assessment

A carers’ assessment is the vehicle in law through which carers are recognised and offered support. In practice, however, the support offered can be limited and fail to meet the full needs of the carer.

Monetary support from a local authority following an assessment can also be both a blessing and a cause of frustration. Aside from Carer’s Allowance, many local authorities offer one-off grants specifically for carers to improve their wellbeing. While such schemes purport to offer freedom for a carer to choose the services they want, applications can be rejected on suitability grounds. Anecdotally, local authorities may support some interventions over others (i.e. healthy lifestyle groups over massage or therapy sessions). A rejected application can leave carers feeling deflated once more, wondering how the promise of a carer’s assessment is translated into reality.

It is therefore important within carers’ assessments for practitioners to have an honest conversation with carers about what they can expect from the assessment, and to give information and advice about any offerings of support from other organisations.

Practitioners’ perspectives

Fragmentation between services

Geography and service specified boundaries can lead to a fragmentation of support and inequality of care. As the Care Act (2014) is the mandate of the local authority, support is provided on a locality basis. The quality of carers’ support is thus influenced by where someone lives. The tensions surrounding this can be particularly heightened at the boundaries between areas, where some individuals are eligible for certain services and others are not. This does not happen in all areas, and depends on the joint working of neighbouring statutory bodies.

Equally, the fact that local authorities can commission NHS trusts and third sector organisations to deliver carers’ assessments introduces further complications. For example, if the individual who is cared for accesses NHS secondary mental health care, their carer can often be given an assessment and support from this trust. If not, their carer would be supported by a different organisation, leading to the possibility of unequal and unfair support.

Funding and resource constraints

Supporting carers has a massive impact on the caring situation, preventing crises and helping families to be self-supporting. However, practitioners can also feel frustrated at the limitations of the support they can give after an assessment has taken place. In a performance-driven society, targets may be set for the number of carers’ assessments to be undertaken each year. When care practitioners are under pressure to achieve these targets and to increase their mental health caseload too, the amount of time they can spend supporting carers and ‘going the extra mile’ may be

curtailed. This has the potential to impact on the quality of the service, and the standard of support a carer may experience. Without adequate support, carers can feel isolated and may subsequently suffer from ill health, further affecting those they care for. Focusing on the quantity of assessments rather than the quality of support can leave carers feeling isolated and unsupported, and put families at risk of crises.

Engaging carers

Traditionally carers were not often perceived as needing support or considered in service design. Since the successive legislation that has improved the rights of carers, this notion has been overturned and carers are seen as active participants in their loved one's care.

Many organisations now have carers' strategies, dedicated carers' support staff, and literature that aids carers in their journey to access support. Some have carers' strategy groups, while others engage carers in the design of certain projects. Surveys, such as that undertaken by the North Essex Partnership University NHS Foundation Trust (n.d), are extremely important in gathering a wide range of views and opinions. Asking carers to design and deliver staff training is another engaging way to incorporate a carer's expertise, and challenge traditional ways of thinking and working.

These initiatives are extremely promising and mark a commitment from organisations to care for the carer, and recognise their need for support.

Good practice case study - South Essex Partnership University NHS Foundation Trust

The South Essex Partnership University NHS Foundation Trust (SEPT) describes itself as a 'carer focused organisation' and has a number of initiatives aimed at supporting carers. The trust has a close relationship with three local authorities in South Essex, which employ carer link workers to work within the trust. When a carer is identified, they are referred to these carer link workers for a carer's assessment. The carer's assessment acts as a 'doorway' to support, provided either by the link workers themselves or by signposting to other organisations. The carer link workers offer one to one sessions, practical assistance, and help with an application for a recovery budget provided by the local authority. They themselves are a network and conduit of knowledge to support carers within the community. They also run two groups, a carers' coffee club and a 'walkie talkie' group, which is supported by a text reminder service. This helps carers exercise and socialise, and mitigates loneliness.

SEPT also runs a 'Your Health, Your Life' carers' course. This is a free course that helps carers to cope with their situation, teaches them new skills, signposts them to support and is a place where carers can get to know each other. It takes place over 6 weeks, and is run and designed by carers and former carers. Carers learn about relaxation techniques, communication, living a healthy lifestyle and carers' rights. The overall aim is to make carers feel that they have more control over their lives. The social aspect and the informal networking is an important outcome. The groups bring carers together, reducing isolation and facilitating a shared network of understanding and problem solving.

Conclusion

Carers' assessments offer carers a 'doorway' to support. They are the mechanism through which professionals can build a relationship with carers, to understand their needs and view the caring situation holistically. Supporting carers adequately has many benefits for carers, service users and the whole family, and is thus crucial to get right.

Mental health carers face unique challenges. The culture and attitudes towards mental health make it even more difficult for these carers to be recognised and be given the support that they are entitled to. And there are difficulties with information sharing that hinder partnership working with carers. We have found that whilst the sentiments of the Care Act 2014 are increasingly being realised in practice, there are many practical, systematic and cultural barriers to its full implementation. Some are specific to mental health, while others are common among other groups of carers.

It is not all bleak, however. Many organisations are attempting to engage with carers and

support them in new and innovative ways. Carers' courses, carer-led staff engagement and carers' strategy groups are all ways that the agenda of carers can be propelled, and ways of working can be improved. This impetus needs to continue until it is fully embedded, and variation in practice no longer exists.

Overall, a full cultural shift needs to occur. The Triangle of Care needs to be fully embedded within all mental health services, and mental health specific issues be overcome (Carers Trust, 2016).

Further research on this topic is essential. Little is yet known about the effectiveness of carers' assessments and what helps or hinders this. We need to find and share examples of best practice across the country and make recommendations to commissioners, local authorities and NHS trusts about where improvements can be made. It is essential for all of us that we support carers fully and remember that it is likely that all of us will either be in receipt of care, or be a carer ourselves.

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