

Implementing the Care Act

for people with fluctuating,
long-term conditions

Produced by

Action for M.E., Arthritis Research UK, Crohn's and Colitis UK, M.E. Association, MS Society, NAT (National AIDS Trust), National Rheumatoid Arthritis Society and Parkinson's UK

Introduction

This briefing sets out local authorities' key responsibilities under the Care Act in relation to people with long-term, fluctuating conditions with care and support needs.

Our organisations represent many hundreds of thousands of people in England with long-term, fluctuating conditions. About 15 million people in England have a long-term condition, many of which will fluctuate.¹ Effective assessment and care planning, and accessible information and advice, enable people to live independently for as long as possible, often minimising the life-time cost of care for both the individual and their local authority.

The Care Act has the potential to significantly improve care and support for people with fluctuating, long-term conditions. Fluctuation must now be taken into account when making eligibility decisions, and recognition of fluctuating needs in care and support plans has been acknowledged in statutory guidance.

The information contained in this briefing is of relevance to everyone with responsibilities for meeting the care and support needs of this group, specifically assessors, care planners, social workers, Directors of Adult Services, social care portfolio holders and commissioners.

¹ Department of Health, Report. Long-term conditions compendium of Information: 3rd edition, 2012

SUMMARY OF KEY POINTS

1. Assessment of fluctuating needs

Assessors should consider fluctuation over both the short and longer term, and the cumulative impact on an individual's wellbeing in reaching eligibility decisions. They should have a good understanding of long-term conditions and 'hidden' symptoms.

2. Recognising fluctuating needs within care and support plans

Care and support plans should include plans for dealing with sudden changes in need so that people do not fall into crisis.

3. Carers and fluctuating needs

Carers needs can fluctuate for reasons related or unrelated to the person they care for. Any carer who appears to have a need for support should be offered an assessment.

4. Accessible information and advice

The right information at the right time can help people to manage their condition and plan for the future, whether or not they are currently eligible for care and support services.

5. Understanding local needs: data collection

Collecting data about the prevalence and nature of long-term conditions at a local level is central to planning how to meet future needs.

What are fluctuating needs?

A fluctuating condition is a chronic condition - physical or mental - where a characteristic feature is significant variation in the overall pattern of ill health and/or disability. Fluctuating conditions are wide-ranging and include Parkinson's, multiple sclerosis (MS), mental health conditions such as depression, inflammatory bowel disease, chronic fatigue syndrome, HIV and rheumatoid arthritis.

The symptoms and experiences of people with fluctuating conditions vary widely and can be difficult to assess. They can require more support and expertise as a result of changing levels of need. Living with a long-term fluctuating condition means life can be very unpredictable, as symptoms can vary over the course of week, day, or even an hour. When symptoms are at their worst, people may need support with washing, dressing and eating. People can become socially isolated, as getting out and about becomes more difficult, impacting on their mental and physical health.²

People with complex, fluctuating conditions require responsive care and support to help them plan for the future and stay as healthy and independent as they can, for as long as possible.

² Evidence of this amongst people with MS is explored in MS Society and Plymouth University research paper, [Social isolation amongst severely impaired people with multiple sclerosis \(MS\): choice, control and identity](#), November 2014.

1. Assessment of fluctuating needs

Fluctuating needs must be taken into account when making eligibility decisions.³ Such needs may not be apparent at the time of an assessment, but have been an issue in the past and are likely to arise again in the future

Assessors should:

- **Look at fluctuation over the course of a day as well as a longer period of time.** Assessing needs on the basis of how an individual presents within the space of a half-hour assessment period would not be sufficient to accurately assess their needs.⁴
- **Consider both the frequency with which a person's symptoms reoccur, as well as the severity of these symptoms.** This means looking at the frequency and severity of the 'bad days' in order to truly assess an individual's average level of capability. However, there may need to be further flexibility in some cases depending on the individual's condition and treatment cycles.
- Consider an individual's medical history and support needs which could indicate future needs.
- Consider the cumulative impact of *multiple* fluctuating conditions. For example, people with HIV who have neuropathy may also experience gastro-intestinal problems and fatigue.⁵
- Have a good understanding of common fluctuating conditions in order to be well placed to identify symptoms associated with such conditions, including hidden symptoms, such as pain, fatigue and problems with cognition. This is vital to understanding the impact of these conditions.
- Be aware that needs may fluctuate not just as a result of an individual's health condition, but also changing circumstances, in terms of employment, living situation, or the health of a family carer, for example.
- Present information in an accessible way and endeavour to ensure that the assessment itself does not put unnecessary strain on the individual. People with long-term conditions can experience cognitive and communication difficulties which can make engaging with complex care processes more difficult.

We would caution against assessors bringing any assumptions to an individual's assessment with regards the care needs they may have. We recognise that the guidance allows for comparison with similar conditions, however, the nature of fluctuating conditions is such that their impact on each individual is highly variable.

Assessors should listen to and learn from each individual to understand the particular impact their condition has on their wellbeing.

3 [Final Affirmative Regulations Under Part 1 of the Care Act](#), p. 14.

4 See clauses 6.58-9 of the [Care and Support Statutory Guidance Issued under the Care Act 2014](#), p. 87.

5 See NAT (National AIDS Trust), [Fluctuating symptoms of HIV](#), August 2011

2. Recognising fluctuating needs within care and support plans

One aim of the care and support planning process should be to design a plan and provision of support that will meet an individual's needs should they increase suddenly.⁶ If a plan and adequate provision is not in place, individuals may be forced to access costly health services, or be left without the support they need to the detriment of their overall health and wellbeing.

Care planners should:

- **Seek to ensure the care and support plan is joined up with any other care plan** that may exist between an individual and their care provider, for example. It may be appropriate for greater detail on how changing needs will be met to reside in one of these other documents. The local authority, however, ultimately has a duty to make sure adequate provision is in place.

EFFECTIVE CARE PLANNING FOR FLUCTUATING NEEDS: EXAMPLE

Miss S has Multiple Sclerosis and requires a frame or wheelchair for mobility. Miss S suffers badly with fatigue, but for the majority of the time she feels able to cope with daily life with a small amount of care and support. However, during relapses she has been unable to sit up or walk, and has lost the use of an arm or lost her vision completely. This can last for a few weeks, and happens two or three times a year; requiring 24 hour support for all daily activities.

In the past, Miss S was hospitalised during relapses as she was unable to cope at home. However, for the past three years, she has received a care and support package that includes direct payments, which allows her to save up one month's worth of 24 hour care for when she needs it, and this is detailed in the care and support plan. Miss S can now instantly access the extra support she needs without reassessment and has reassurance that she will be able to put plans in place to cope with any fluctuating needs. She has not been hospitalised since.⁷

⁶ Clause 10.44 of the [Care and Support Statutory Guidance](#), p.175

⁷ Ibid, p.178

3. Carers and fluctuating needs

The needs of carers can also fluctuate and the same principles apply to them as to people with care needs. A carer is anyone who cares, unpaid, for a friend or family member who, due to illness or disability, cannot cope without their support. Supporting carers to maintain their wellbeing has multiple benefits. If a carer's needs are not met, their health, and/or that of the person they care for, can deteriorate and require more costly health interventions.

Advice for assessors:

- When undertaking an assessment of an individual with care and support needs, **assessors should seek to identify any carer(s)** or potential carer(s) and should offer them a carers' assessment, regardless of whether the person they care for has been found eligible for care and support.
- A carer's needs may change as a result of the changing needs of the person they care for, or for reasons independent of that person. For example, ill health of their own, other caring responsibilities, or changes in employment.
- Consider what the nature of a carer's needs has been **over the past year** to get a complete picture of their level of need.
- A carer's care and support plan should detail how their fluctuating needs will be met. Meeting a carer's fluctuating needs might include provision of home care to support the person they care for some of the time, or a choice of respite options that can be taken when they are most needed, enabled through a direct payment, for example.⁸

4. Accessible information and advice

Many people with long-term conditions, and their carers, may find themselves ineligible for statutory support at a given point. However, the right information at the right time can help them to manage their condition and plan for the future.

The duty to establish and maintain an information and advice service is distinct from the duty to meet eligible needs. A lack of clear information about social care processes and entitlements can be a barrier to self-referral meaning people delay seeking the help they need and their needs can escalate.

Local authorities should ensure:

- Information and advice includes advice on how the care and support system works, how to plan for future care needs and how to pay for them, and advice for carers.
- If no eligible needs are identified following an assessment, individuals are provided with information on what community services and universal provision are available to support them.

⁸ See clauses 6.136-7 of the [Care and Support Statutory Guidance](#), p.110

5. Understanding local needs: data collection

It is estimated that by 2030 around 40% of the UK's working age population will have at least one chronic and work-limiting health condition.⁹ Understanding the needs of their local populations will enable local authorities to plan for and commission appropriate services to meet present and future needs.

Local authorities should:

- Consider collecting data on specific conditions and multiple and complex needs to help shape the commissioning of appropriate and effective services for people with long-term fluctuating conditions.¹⁰
- Collect feedback from service users, families and carers, and engage more widely with voluntary and community services, and supported housing providers, for example, in order to shape services.¹¹

9 The Work Foundation, [Fluctuating Conditions, Fluctuating Support: Improving organisational resilience to fluctuating conditions in the workforce](#), 2015

10 Clause 4.71, [Care and Support Statutory Guidance](#), p.57

11 Clause 4.72, p.57

Produced by Action for M.E., Arthritis Research UK, Crohn's and Colitis UK, M.E. Association, MS Society, NAT (National AIDS Trust), National Rheumatoid Arthritis Society and Parkinson's UK

Please get in touch with the relevant organisation should you require information, advice or training relating to a particular condition.



Action for M.E.

Action for M.E. is the UK's largest charity for people affected by the long-term, disabling condition myalgic encephalomyelitis (M.E.), sometimes diagnosed as chronic fatigue syndrome (CFS, or M.E./CFS). Our mission is empowering people with M.E. to fulfil their potential and secure the care and support they need, while working towards a greater understanding of the illness and ultimately a cure. www.actionforme.org.uk



Arthritis Research UK

Arthritis Research UK is the charity dedicated to stopping the devastating impact that arthritis has on people's lives. Our long term commitment is prevention, developing a cure, and transforming the lives of those with arthritis. We fund research into new treatments to end the pain of arthritis, and provide information on living well with arthritis. www.arthritisresearchuk.org



Crohn's and Colitis UK

Crohn's and Colitis UK is the leading charity in the battle against Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD). Our mission is to work with all those affected by these conditions to achieve a better quality of life, improve services, and ultimately find a cure. www.crohnsandcolitis.org.uk



M.E. Association

The ME Association speaks up for 250,000 children and adults in the UK who have myalgic encephalopathy, which is also known as chronic fatigue syndrome. www.meassociation.org.uk



MS Society

The MS Society is the UK's largest charity for people living with multiple sclerosis (MS). We're here for everyone living with multiple sclerosis - to provide practical help today, and the hope of a cure tomorrow. We play a leading role in research. We fight for better treatment and care. We let people with MS know they're not alone, and offer advice and support to help them manage the symptoms. www.mssociety.org.uk



NAT (National AIDS Trust)

NAT (National AIDS Trust) is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expertise and practical resources. We champion the rights of people living with HIV and campaign for change. www.nat.org.uk



National Rheumatoid Arthritis Society

The National Rheumatoid Arthritis Society is 'the voice' of people affected by Rheumatoid Arthritis (RA) across the whole of the UK. Founded in 2001, we are the only UK charity devoted specifically to RA and JIA. www.nras.org.uk



Parkinson's UK

Parkinson's UK is here to make sure people have whatever they need to take back control - from information to inspiration. We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure. www.parkinsons.org.uk