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Informal carers: health and wellbeing

Informal and unpaid carers provide vital support for many people with health and social care needs. However, there is growing evidence that the demands of caring are increasingly impacting carers' own physical and mental health. This has led to calls that unpaid caring should be considered a [social determinant of health](#).

The [Carers Action Plan 2018–2020](#), published by the previous government, included a commitment for NHS England and the Care Quality Commission to develop quality standards for GP surgeries to support carers. [Supporting carers in general practice](#) is a framework of quality markers for improving how general practice can better identify and support carers of all ages. The [NHS Long Term Plan](#) of January 2019 repeated a commitment to improve how the NHS identifies unpaid carers, and to better address their health needs.

1 How caring impacts an individual's health

The charity, Carers UK's survey, [State of Caring 2023](#), found a lack of support and recognition from health and care services was taking its toll on unpaid carers. 82% of carers said the impact of caring on their physical and mental health would be a challenge over the coming year – an increase from 77% from the previous year. The survey also found:

- over three quarters (79%) of carers felt stressed or anxious
- half of carers (49%) felt depressed

- half of carers (50%) felt lonely
- nearly three quarters (73%) said they continued providing care even though they felt they were at breaking point.

The survey reported carers felt a lack of recognition about their caring roles affected their wellbeing: some felt invisible or forgotten about. 55% of carers said they needed better understanding and recognition of unpaid carers from the general public.¹

Carers UK analysis of the [2021 GP Patient Survey](#) found carers were more likely to be in poor health than the general population, with 6 in 10 (60%) of carers surveyed stating they had a long-term condition, disability or illness compared to 50% of those who weren't caring. Of these carers, almost two-thirds (64%) reported that this condition reduced their ability to carry out day-to-day activities.²

Carers UK called on the government to ensure that caring is considered as part of programmes to combat health inequalities, with more targeted work recognising caring as a “social determinant” of health.³ Its [2023 State of Caring survey](#) also recommended an integrated approach to the identification, assessment and support of carers' health and wellbeing needs across all NHS settings, to properly support unpaid carers and those they provided care to.⁴

1.1

Access to health services

Carers' organisations have raised concerns about difficulties faced by carers accessing health and social services for themselves, and for the people they care for. NHS England research from 2013 showed health professionals only identified around one in ten carers, and 66% of carers felt that healthcare staff didn't help to signpost them to relevant information or support.⁵

The Carers UK State of Caring Survey 2023 found 39% of carers whose mental health was bad or very bad said they were not receiving any support with their mental health. The most commonly reported barrier to seeking support for themselves was that they were too busy with their caring duties (50%). Another common barrier was concerns over long waiting times for

¹ [State of Caring 2023 – The impact of caring on: health](#) (PDF), November 2023, p22

² Carers UK, [State of Caring 2021](#), November 2021

³ Public Health England, [Caring as a social determinant of health: review of evidence](#), March 2021

⁴ Carers UK, [State of Caring 2023 – The impact of caring on: health](#) (PDF), November 2023, p45

⁵ NHS England, [Commitment to Carers](#) (PDF), April 2014; NHS England, [Carer facts- Why investing in carers matters](#)

support (31%) and the feeling that services would not meet their needs (28%).⁶

Earlier research from Carers UK found widespread problems faced by carers in accessing primary and community support services for the people they cared for.⁷ Carers UK stressed the importance of the NHS recognising and taking into account the huge contribution of carers, especially when developing services to support out of hospital care. The charity proposed introducing “Carer Passports” as one way in which the NHS could make sure that carers were identified and signposted to available support.⁸

As part of its [Commitment to carers programme](#) (launched in 2014), NHS England published [An integrated approach to identifying and assessing Carer health and wellbeing](#) (PDF) in May 2016, setting out approaches to joint working between organisations. This also set out principles for improved support for carers, including:

- Improving the identification and assessment of carers in primary care.
- Providing an integrated support package to help carers with physical and mental health needs.
- Giving carers choices about how support is delivered.⁹

The [NHS Long Term Plan](#), published in January 2019, repeated the commitment to improve how the NHS identifies unpaid carers, and strengthen support for them to address their individual health needs.¹⁰ This included a commitment to “encourage the national adoption of carer’s passports.”¹¹

In May 2023, the previous government said it had “no plans to assess the potential merits of introducing a national carers passport scheme”.¹² However, Carers UK and the charity Carers Trust, with funding from the Department of Health and Social Care, are working in partnership to help local areas introduce [Carer Passports](#) in five key settings: hospitals, employment, community, education and mental health trust.¹³

⁶ [State of Caring 2023 – The impact of caring on: health](#) (PDF), November 2023, p17

⁷ Carers UK, [Pressure Points: carers and the NHS](#), September 2016 (no longer available online)

⁸ Carers UK, [Carer Passports](#), March 2016 (no longer available online)

⁹ NHS England, [An integrated approach to identifying and assessing Carer health and wellbeing](#) (PDF), May 2016, para 3.3.

¹⁰ NHS England, [NHS Long Term Plan](#), January 2019

¹¹ [As above](#), para 2.33

¹² PQ 185307 [[on Carers](#)], 22 May 2023

¹³ [Carer Passport schemes](#)

Guidance for identifying unpaid carers

In 2019 [NHS England published a 'framework of quality markers'](#) for how general practice can better identify and support carers.¹⁴ The [Royal College of General Practitioners \(RCGP\) has also published learning resources](#) on supporting carers.

The National Institute for Health and Care Excellence (NICE) published [Guidelines for supporting unpaid adult carers](#) in January 2020. It set out the responsibilities of local authorities and NHS organisations (such as GPs, pharmacists and hospitals) to identify, support and involve carers when assessing and planning services.

The previous government said it was working with NHS England and the Carers Partnership, to produce a social prescribing summary document to be disseminated to local carers' organisations to make the offer to carers in England more consistent.¹⁵ The [Social prescribing good practice and top tips resources](#), published in 2022, highlight good practice:

- in social prescribing and interventions that combat loneliness for carers;
- for ensuring social prescribing and other interventions serve communities who face additional barriers to accessing services - namely carers from the LGBTQ+ communities, and carers from ethnic minority communities.¹⁶

1.2

Sharing patient information with carers and involvement in care

Difficulties can arise when health and social care staff must balance the need to inform families and carers with professional and legal requirements to protect patient confidentiality. In most cases, these issues are avoided by a patient giving consent for their private information to be shared. However, staff may need to decide what is in the patient's best interest before sharing information if the patient lacks capacity to consent.

When considering whether to share confidential information with a carer or family member, the [NHS confidentiality guidance for health and care staff](#) (PDF) should be followed:

¹⁴ NHS England, [Supporting carers in general practice: a framework of quality markers](#), June 2019

¹⁵ PQ102668, [on [Carers: Finance](#)], 2 March 2022

¹⁶ Carers Trust on behalf of the Health and Wellbeing Alliance, [How-to-guide: Social prescribing good practice and top tips](#), 2022

- Professionals should establish with the service user or patient what information they want to be shared, with whom, and in what circumstances.
- Confidential information should be shared with the carer when the service user or patient has given explicit, informed consent and when the carer consents to be told.
- Where the service user or patient does not have capacity to give valid consent, confidential information should be shared with the carer where it is in the person's best interests.¹⁷

Chapter 5 of the [Code of Practice](#) (PDF) to the [Mental Capacity Act 2005](#) (MCA) provides detailed guidance for health and social care staff on taking "best interests" decisions, where someone lacks capacity. Health and social care staff have a duty under section 4(7) of the MCA to take into account the views of anyone involved in caring for the person and anyone interested in their welfare (for example family carers and other close relatives) as part of a best interests decision.

NICE recommends carers are involved in decisions about patient's hospital discharge plans, if the patient and their carers agree.¹⁸ NICE's [Guidelines for supporting unpaid adult carers](#) also recommends NHS providers should "share with carers the information they need to provide care effectively and safely while respecting confidentiality (explain to them the constraints of confidentiality)".¹⁹

¹⁷ NHS Digital, [A guide to confidentiality in health and social care](#), 2013, Chapter 6, rule 2.

Information can also be found in [NHS England's Use and share information with confidence](#)

¹⁸ NICE, [Transition between inpatient hospital settings and community or care home settings for adults with social care needs Quality standard](#) [QS136], December 2016, Quality Standard 5. Each hospital has its own discharge policy which should be available from the ward manager or the hospital's Patient Advice and Liaison Service (PALS).

¹⁹ NICE, [Supporting adult carers](#), January 2020, para 1.1.12

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