

Spotlight on...

Caring and Nutrition



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Foreword

Helen Walker,
Chief Executive, Carers UK



Most of us will care at some point in our lives and some of us will care several times. Yet very few of us are prepared for that journey. One of the most important things carers tell us is that it's essential to get the right information at the right time to care safely and well.

But this doesn't always happen; partly as a result of services not recognising carers and understanding that they need key information and partly because carers can take years to recognise themselves as carers and don't always know the questions to ask or where to get the right advice. As a result, carers without the right information, advice and expert support experience higher levels of stress, anxiety and ill health – a situation we believe can and should be addressed.

We know directly from carers that nutrition is often a hidden issue that needs to be tackled. Most information and advice for carers concentrates on benefits, welfare, work, the condition of the person being cared for and social care. Yet when we see the levels of carers' worry about nutrition and hydration and the benefits that good nutrition and hydration can bring to people needing care, it's clear that this nutrition and hydration should be a key part of many carers' journeys.

This research has key messages for all – whether it's the Governments in England, Scotland, Wales or Northern Ireland, the NHS, local authorities commissioning services, service providers or carers themselves. It provides both impetus and solutions about supporting carers, making good nutrition a key part of help that families receive.

We have been delighted to work in partnership with Nutricia over the years to raise the profile of good, trusted information, advice and support to achieve good nutrition and this research underlines the continued need for that focus.

Given that we know the increased stress, worry and anxiety that carers face, it makes sense to ensure that they are better supported. The more that we can invest in making sure that carers have the information, advice and support, the better the outcomes for everyone.

Helen Walker, Chief Executive, Carers UK

Foreword

Victoria Blewett
Medical Affairs Director, Nutricia



Malnutrition is increasingly common in the UK, affecting an estimated 1 in 20 people. It is more prevalent in the elderly and those with existing illness, affecting 1 in 10 people over the age of 65 years old. Yet, it is a condition that is often underdiagnosed and undertreated.

Being malnourished can reduce quality of life, slow recovery and cause physical decline, which is often accompanied by a deterioration in mental health. It is because of these common effects that compared with the average, those who are malnourished are twice as likely to visit their GP and three times more likely to be admitted to hospital, where they stay on average three days longer than patients with a healthy weight.

At Nutricia, we have made it our mission to bring health through nutrition to as many people as possible. We do this by providing nutritional solutions to a wide range of people, including those who can't get the nutrition they need through food alone. We are also committed to help raise awareness about the importance of a balanced diet on health outcomes, notably through our partnership with Carers UK and we were delighted to support this report.

We must all work together to help detect the signs of malnutrition or dehydration, as the earlier it is spotted, the easier it is to manage. Carers in particular have an important role to play, as they are often in close proximity with people who are at risk. They should look for signs such as weight loss (e.g. looser clothing), empty fridges, or lack of energy and tiredness from the people for whom they care. Self-screening tools such as the Malnutrition Universal Screening Tool ('MUST') can easily be downloaded online and I would encourage all carers to do so.

Healthcare professionals also need to keep nutritional care at the forefront of their minds. Part of this comes from an educational exercise, but also the need for guidelines on how to prevent, diagnose and manage malnutrition to be implemented more consistently across all care settings. Additionally, a standardised nutritional screening process and integrated management pathway in primary and secondary care, and in the community, would go a long way in improving patients' outcomes and ultimately reducing pressure on the NHS.

Victoria Blewett, Medical Affairs Director

Summary

Diet, nutrition and hydration is an under-recognised issue across the UK, but better and earlier interventions, information, advice and support could transform the lives of people needing care as well as their families who support them. This research looks at unpaid carers' worries and concerns when the person they care for is underweight or overweight. It also looks at where people get their information and advice from, which is key to helping them address these worries and concerns.



Nutrition plays a critically important part in the wellbeing and recovery of an individual. When a person is malnourished their energy, strength and ability to heal can be reduced. This can lead to unnecessary or prolonged illness, with greater pressure placed on both carers and health services as a result. This can particularly affect the most vulnerable people in society, who will often have the greatest care needs.

Given that 93% of patients experiencing malnutrition are in the community¹ and the fact that the majority of care and support is provided by unpaid carers, it's important to ensure that unpaid carers are equipped with the right information, advice and support, including medical intervention where necessary, to help manage nutrition. Carers have told us how emotionally challenging it can be to support someone who is underweight, when they find it hard to eat or take on nutrition.

¹ Commissioning Excellent Nutrition and Hydration Services, Commissioning Guidance, NHS England, 2015 www.england.nhs.uk/commissioning/nut-hyd

The British Association for Parenteral and Enteral Nutrition (BAPEN) estimated that malnutrition costs the UK economy £23 billion per year, much of which is preventable with the right information, advice and intervention, as well as spotting the signs of under-nutrition as early as possible.²

Malnutrition is commonly underdiagnosed and, despite the pressure it puts on the health and care system, is an issue that is talked about far less than over-nutrition and obesity. Supporting healthy nutrition is part of many different specialisms of medicine, with dietetics at its heart, crossing health and social care. Whilst national guidelines exist, implementation is inconsistent across the health and social care system. This report recommends a series of interventions which could mobilise better information, advice and support.

Being overweight is associated with many health risks which are well known and documented. This report sets out the worries that carers have in relation to the person they care for if they are overweight. Whilst reducing obesity is a national public health target, much more could be done to support people who have disabilities and long-term conditions to manage their weights, particularly if specific advice is needed or additional targeted support e.g. social care support.

Although we did not ask any questions about the cost of living in relation to nutrition, it is clear from some unpaid carers' responses that for those on lower incomes, this puts pressure on their ability to support someone to address under-nutrition or someone who is overweight.

Our results found that:

- One in seven carers (14%) were caring for someone with a disability or illness who was underweight.
- 39% of carers were caring for someone who was overweight.
- A large proportion of carers worry about the diet and nutrition of the person being cared for – between half of all carers to six out of ten depending on the area of worry.
- Carers of people who were underweight were most likely to be worried about diet, nutrition and hydration.
- Those most likely to be underweight tended to be older people, the carers' parents or parents-in-law and not living with the carer.



² The cost of malnutrition in England and potential cost savings from nutritional interventions (short version), M Elia, BAPEN, and the National Institute for Health Research Southampton Biomedical Research Centre, 2015 www.bapen.org.uk/pdfs/economic-report-short.pdf

In terms of carers of people who were underweight:

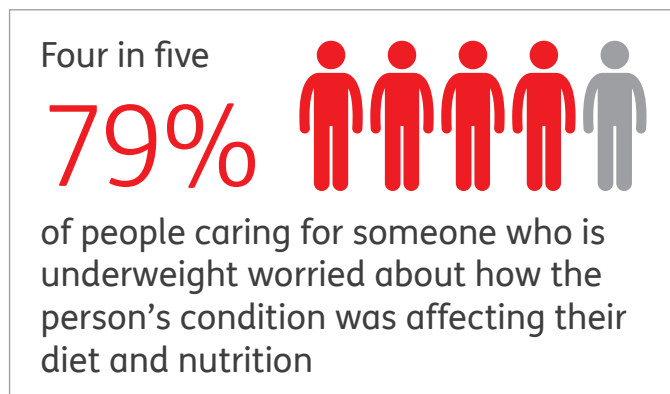
- Eight out of ten carers (79%) worried about how the person's condition was affecting their diet and nutrition.
- Seven out of ten carers (68%) worried about how to manage diet and nutrition alongside the person's condition.
- Seven out of ten carers (72%) worried about hydration.

One in seven (14%) of all carers said that the person they cared for had experienced rapid weight loss but this rose to 45% of carers of people who were underweight.

When it came to advice, the most popular source was the internet for all carers at 34%. One in seven carers (13%) received advice from a dietitian, and this rose to 26% for carers who were underweight.

Despite the small sample size, it's also clear that there are differences between different cultural and ethnic groups in terms of worry about diet and nutrition.

The results point towards several opportunities to reduce carers' worry and concern about diet and nutrition, improve their knowledge about these issues and achieve better and more positive outcomes for themselves as well as the health and wellbeing of the person being cared for. The guidance developed by NHS in 2015 contains important evidence which points towards key benefits for health and care services, as well as families, such as lower demands on general practice, shorter hospital stays and other key elements of the health economy.³



The recommendations we set out below are deliverable and achievable across different health and care structures as well as through services in the UK, regardless of where the carer and the person being cared for lives, as long as diet and nutrition is an integral part of care being provided.

Given the pressures on health, social care and families, it makes economic sense to ensure that malnutrition is prevented and that issues associated with being overweight are also tackled for our long-term health and wellbeing.

Overarching recommendations relating to diet and nutrition

1. As diet and nutrition is a core part of people's wellbeing, it should be part of every health body's strategy to prevent ill-health and to challenge and tackle health inequalities. This strategy needs separate and dedicated approaches – one to tackle malnutrition and the other to support people who are overweight.
2. Care and carers' assessments under the Care Act 2014 (England) could be activated more to help with information, advice and support. These assessments include the statutory eligibility criterion: "ability to maintain nutrition", which provides a basis on which to ensure that there is appropriate tailored support. It is vital that people assessing unpaid carers, or the people they are responsible for, are able to understand the risks of under-nutrition as well as being overweight and ensure that the right information, advice and links are made with key health bodies or with community-based support.
3. To improve health outcomes, the use of patient and carer data needs to be maximised by flagging unpaid carers clearly on the patient's care record, as well as the carers' own record, to ensure that they are included and supported to help manage the nutrition of the person being cared for. This is particularly important where someone is at risk of malnutrition. It would also help to target proactive strategies to help people with weight loss.
4. Improve the knowledge and use of good quality internet-based information and advice as this is an important source for unpaid carers and provides an opportunity to maximise tailored support, particularly as a first step.

5. Ensure greater digital inclusion for people on low incomes or who are less confident about using the internet to ensure equality of access to this kind of information and advice, through local authorities, internet providers and health budgets where necessary.
6. Maintain traditional methods of information and advice i.e. face to face or via telephone, which remain critical for people not connected to the internet or are necessary to gain a different perspective.
11. Local health bodies should ensure that planning, systems, awareness and support measures are appropriately accessible and tailored for unpaid carers and patients from Black, Asian and ethnic minorities and different faiths.
12. All local health systems need to adopt a systematic and preventative approach whereby:
 - All patients at risk are screened for malnutrition before transferring into a community or home setting.
 - Patient pathways include support for malnutrition within both the primary and secondary care settings.
 - Links between frailty and malnutrition are addressed with simple measures such as embedding the malnutrition risk score alongside frailty screening for the elderly.

Specific recommendations to support carers of people who are underweight

These recommendations apply in principle to the whole of the UK, but we have referenced England related institutions or bodies in some specific recommendations.

Strategic planning and commissioning

7. A clinical lead for nutrition should be appointed within Government to manage the integration and implementation of policy on malnutrition into other strategic areas. Evidence suggests that tackling malnutrition could help to reduce admissions to hospital, reduce hospital stays, improve hospital discharge outcomes, improve recovery and reduce pressure on primary care services.⁴
8. NHS England to consider a refresh of the commissioning nutrition and hydration guidance published in 2015 to relate to the new Integrated Care Board (ICB)s' responsibilities and duties.⁵
9. Health bodies, e.g. in England, Integrated Care Boards and Integrated Care Partnerships (ICP), need to ensure that strategic planning engages all relevant parts of the Integrated Care System (ICS), with a particular focus on preventing and treating under-nutrition. This should be directly linked to duties to reduce health inequalities and prevent ill-health.
10. Local health bodies should ensure that there is accessible information on preventing or treating under-nutrition which can be easily accessed, e.g. in pharmacies, GP practices, and in local charities which support disabled, ill, or older people or unpaid carers.

Awareness

Awareness of under-nutrition needs to be increased as well as simple ways to identifying the condition, especially when it is preventable.

13. Every local health area, e.g. ICB in England, should have a rolling awareness programme which seeks to prevent malnutrition by encouraging widespread knowledge of the causes, symptoms and effects of malnutrition.
14. There should be a specific awareness raising programme with health and care staff around recognition and prevention.
15. Local carers' organisations should understand and be aware of the risks of under-nutrition and the importance of information, advice and support for unpaid carers.
16. Local carers' organisations should include regular information for carers on spotting the signs of malnutrition for people who are at risk of being underweight as well as simple ways to address this.
17. Health and care staff also should be raising awareness more broadly with unpaid carers about under-nutrition, ways to spot it and the steps to take if someone is at risk. This could include regular utilisation of tools such as the MUST online screening tool.⁶

⁴ Ibid

⁵ Ibid

⁶ Malnutrition Universal Screening Tool www.bapen.org.uk/pdfs/must/must_full.pdf

Support

- 18.** Health and care systems need to provide unpaid carers with the practical support and interventions for the person they care for to be able to deal with under-nutrition or malnutrition with access to specialist advice.
- 19.** Health systems need to provide specific support for unpaid carers who are on low incomes to prevent under-nutrition as well as effectively tackling malnutrition.
- 20.** Health and care systems should promote the use of assisted living technology or off the shelf wearable tech to help carers who do not live with the person they care for to monitor nutrition and hydration levels and to raise awareness of the valuable role that this can play for carers in reducing anxiety.
- 21.** Health and care systems should follow the Malnutrition Taskforce tips about to help prevent malnutrition.



Recommendations for supporting people caring for people who are overweight

Strategic planning and commissioning

- 22.** A clear Government lead is needed on policies and actions to support people with disabilities and unpaid carers who are overweight, i.e. whole family approaches to tackle managing healthy weights with clear links to income, social care, specialist health advice for particular conditions and health prevention strategies.
- 23.** The Office of Health Improvement and Disparities (OHID) should consider a programme of support for unpaid carers supporting people who are overweight.
- 24.** Supporting carers needs to be a specific part of health bodies' delivery of reduction of health inequalities.
- 25.** There should be continued strategic support by Sport England for nationally led programmes such as We Are Undefeatable and Carers Active.
- 26.** Locally set targets which systematically invite unpaid carers for health checks which include advice on nutrition.
- 27.** Greater use of social prescribing and personal budgets to support carers' health and wellbeing as well as the people they care for.
- 28.** Allow greater access to specialist advice and information when needed for carers, including health information related to particular disabilities.

Specific support for carers on low incomes

- 29.** Support for carers and their families on low incomes to be able to maintain a healthy diet and exercise.

1. Introduction and context



About carers – who they are and what they do

The 2021 Census found that there were around 5.7 million carers in the UK, including 5 million in England and Wales (9% of the population). Although the overall number of carers has declined since 2011, the intensity of care (i.e. the number of hours of care provided) has increased. 4.7% of the population are providing over 20 hours of care a week. 1.5 million people are spending over 50 hours of week on unpaid care.⁷ Carers UK's most recent polling suggested that the number of unpaid carers could be far higher at 10.6 million across the UK if a broader definition is used that helps unpaid carers to identify themselves as such.⁸

The care that is provided by carers ranges from emotional support to complex medical tasks and everything from an hour or two per week, to 24 hours, around the clock care.

The care provided by carers pre-pandemic was worth £132 billion a year, equivalent to the NHS budget.⁹ It is now estimated that carers save the state £530 million a day or £193 billion greater than the value of the NHS.¹⁰

⁷ Census 2021, January release, 2023, Office of National Statistics

⁸ Carers Week 2022 report, Carers UK

⁹ Valuing Carers 2015, Carers UK, 2015 www.sheffield.ac.uk/news/polopoly_fs/1.5464091/file/Valuing-Carers-2015.pdf

¹⁰ Carers Rights Day research 2020 – news release – www.carersuk.org/press-releases/unpaid-carers-save-uk-state-530-million-every-day-of-the-pandemic

About nutrition and hydration and why it matters

Nutrition and hydration are important issues in caring. They do not always appear at the top of the agenda, but they are often sources of constant worry for unpaid carers. This includes whether an unpaid carer is responsible for helping someone with their nutrition or being alert to any changes if someone else is responsible for their care, for example in, a care home, paid care staff or in hospital.

The National Institute for Health and Care Excellence (NICE) defines malnutrition as: “a state in which a deficiency of nutrients such as energy, protein, vitamins and minerals causes measurable adverse effects on body composition, function (including social and psychological) and clinical outcome.” (NICE Quality standard [QS24], 2012)

It is estimated that 93% of patients experiencing malnutrition are in the community. One in three patients admitted to hospital pre-pandemic were at risk of malnutrition or malnourished and 35% of people admitted to care homes were in a similar position.¹¹

Nutrition plays a hugely important part in the role of the wellbeing and recovery of an individual. When a person is malnourished their energy, strength and ability to heal can be reduced. This can lead to unnecessary or prolonged illness, with greater pressure placed on both carers and health services as a result. This can particularly affect the most vulnerable people in society, who will often have the greatest care needs.

“Malnourishment can affect health and well-being, and cause long-term health problems for otherwise healthy and independent older people. It can also mean more visits to the GP, increased chances of being admitted to hospital and longer recovery times from illness.”¹²

Some groups of people are more at risk of poor nutrition, and they include:

- Older people
- Some people who are overweight but don't have a nutritious diet
- People whose illness or condition affects their appetite or ability to eat/absorb nutrients
- Some children or adults with very particular eating habits, e.g. are neurodiverse
- People with eating disorders.

There are particular challenges with certain conditions such as dementia, especially when people are caring at a distance.

As an example, older people quite often have reduced appetites, or eating may take much longer, and they stop eating before they have consumed sufficient food. Loneliness may also make this worse if they are not eating with company.



¹¹ Commissioning Excellent Nutrition and Hydration Services, Commissioning Guidance, NHS England, 2015 www.england.nhs.uk/commissioning/nut-hyd

¹² Malnutrition Taskforce www.malnutritiontaskforce.org.uk/eating-well



The important role of hydration and its role with nutrition

Hydration is equally important and has significant health effects. The scale of dehydration in the UK is unknown according to NHS England.¹³

Dehydration can be defined as: “a state in which a relative deficiency of fluid causes adverse effects on function and clinical outcome. In the elderly being short of fluid is far more common, results from limited fluid intake, and is reflected in raised osmolality”.⁵

“Hydration is a big worry for me as a carer. I am continually reminding my husband to drink.”

Measuring someone’s hydration levels when caring for them at home, or even more so at a distance can be very challenging.

“He does not drink enough water and only drinks it when I am around.”

What is the carer’s role in nutrition and hydration and what challenges are there?

Carers often play a critical role in the nutrition and hydration of the person they care for. This ranges from being alert to whether the person they care for gains or loses weight, to being wholly responsible for the diet, nutrition and hydration of the person they care for. This can include complex diets, medical nutrition and psychological support – not just in relation to eating disorders, but other conditions as well.

¹³ Commissioning Nutrition and Hydration, op cit

2. Who are the carers in this research?

The research included in this report is based on Carers UK's State of Caring survey 2021. Over 8,000 carers in the UK took part in the survey. The following results are based on UK results, with results for Wales, Scotland and Northern Ireland contained in the Annexes to this report.



The respondents in this survey are overwhelmingly likely to be providing significant care and are therefore more likely to be caring for people with complex or multiple conditions needing more support. 82% of respondents cared for over 35 hours a week and 54% cared for more than 90 hours a week. This level far outstrips the level of caring in the Census 2021 where just under one third of all carers provide over 50 hours of care per week.¹⁴

The kinds of care the respondents provide is as follows:

- **Practical help** (e.g. preparing meals, shopping, laundry, housework, household repairs, taking to doctor/hospital) – 94%
- **Providing emotional support, motivation or keeping an eye on someone either in person, or by phone or online** – 88%
- **Arranging/coordinating care and support, medical appointments and other help** – 86%
- **Helping with paperwork/financial matters** (e.g. writing letters, filling in forms, dealing with bills, banking) – 86%
- **Taking the person you care for out and supporting leisure activities** (e.g. taking them out for a walk or drive, or to see friends and relatives) – 81%
- **Helping with medication** (e.g. making sure they take pills, giving injections, changing dressings) – 76%
- **Personal care** (e.g. dressing, bathing, washing, shaving, cutting nails, help with eating, using the toilet) – 67%
- **Help with moving around** (e.g. with walking, getting up and down stairs, getting into and out of bed) – 52%.

¹⁴ 2011 Census Date, Office for National Statistics, 2011 www.ons.gov.uk/census/2011census/2011censusdata

Respondents to the survey were more likely to be female, with 78% identifying as female and 21% identifying as male.

Half of the carers who answered these questions cared for someone with a physical disability while 34% cared for someone with a mental health condition.

Over three quarters (76%) of respondents live in England, 11% live in Wales, 7% live in Scotland, and 6% live in Northern Ireland.

The vast majority of respondents (89%) identified as White, while 2% identified as Asian, and 1% identified as Black.

Who are they caring for in terms of weight?

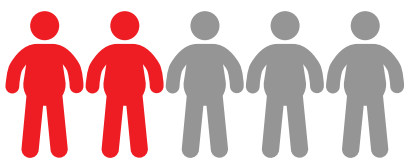
The Carers UK's 2021 State of Caring survey found that while 43% of carers in the UK care for someone considered to be a 'healthy' weight, four out ten carers (39%) care for someone overweight and 14% care for someone underweight. A small minority of carers (4%) reported that they did not know whether the person they care for is overweight or underweight.

Table 1: Percentage of carers looking after people of different weights

Weight category	Percentage
Overweight	39%
Underweight	14%
Healthy weight	43%
Don't know	4%

Two in five

39%



of carers are caring for someone who is overweight

Characteristics of carers of people of healthy weight

We looked at whether there were any different characteristics for carers of people of healthy weight. Carers who reported that their own health was "very good" or "good" were more likely to say that they were caring for someone of healthy weight. 52% of carers with very good or good health reported caring for someone of a healthy weight compared with 43% of all carers.

Carers of people of healthy weight were only very slightly more likely to be women – suggesting that there is very little gender effect (80% of all respondents were female compared to 82% of respondents who were female and caring for someone of a healthy weight).

A majority of carers (63%) who cared for someone of a healthy weight also cared for someone who was older between the ages of 65-90.

Carers who identified as having a disability themselves were more likely to report that they cared for someone overweight or underweight compared with all respondents, with 28% caring for someone underweight and 33% caring for someone overweight. 23% of carers with a disability cared for someone of a healthy weight. These findings suggest that information, advice and support should be targeted and could help to reduce health inequalities.



One in seven

14%



of carers are caring for someone who is underweight

Characteristics of carers who didn't know the weight of the person they cared for

Only 4% of unpaid carers in this survey did not know the weight of the person being cared for. We looked at the different characteristics of this group of carers across age, gender, number of hours of care per week and ethnicity. The following areas are where we found differences:

Women were only very slightly less likely to answer that they didn't know whether the person they cared for was a healthy weight, overweight or underweight.

Asian carers were also less likely to know the weight of the person they cared for. While 2% of total respondents were Asian, 4% of people who did not know whether the person they cared for was overweight, underweight, or a healthy weight identified as Asian.

Whilst this is a very small sub-set of this group of carers, it's more likely that people with lower-level caring responsibilities or people caring at a distance are less likely to know the weight of the person being cared for. This is where advice and information and simple awareness tools can make a difference.

Carers' worries about diet, nutrition and hydration

Properly managing the diet and nutrition of the person you care for can be confusing, stressful and time-consuming. We asked carers to reflect on what worries them most about managing the diet of the person who they care for.

The biggest worry for all respondent groups is how the condition of the person they care for affects their diet and nutrition. This worry is particularly prominent for people who care for someone underweight, with eight out of ten of these carers (79%) agreeing that this is one of their worries.



Table 2: Carers' worries about diet, nutrition and hydration

Strongly agree or agree	Healthy weight	Underweight	Overweight	Don't know	All weights
I worry about how to give a balanced diet to person being cared for	38 %	59%	52%	43%	47%
I worry about how to manage their diet alongside their condition	37%	68%	59%	45%	50%
I worry about how their condition affects their diet and nutrition	51%	79 %	69%	62%	60%
I worry that the treatments impact on their diet and nutrition	27%	44%	46%	30%	37%
I worry about the hydration of the person being cared for	50%	72%	51%	52%	54%

The table above highlights that the least significant worry for all carers is the impact that treatments have on the diet and nutrition of the person they care for, with an overall figure of just 37% of carers answering that they agree that this is something they worry about.

What Table 2 shows is that everyone worries about diet, nutrition and hydration if they are providing significant care, even if they are considered to be a healthy weight. Carers of people who are underweight worry the most out of all carers about diet, nutrition and hydration.

“As a result of their epilepsy, the person I care for has cognition issues in addition to mental health issues and favours sweet and fatty foods – having little appetite for anything besides those. I find it hard to encourage them to have a more balanced diet, and believe that they will miss meals in an attempt to lose weight but still chose to eat unhealthy things as they aren’t able to make the connection between cause and effect. They need frequent reminders to drink water as well as to eat meals”

Generally, people who lived in the same home as the person they cared for were less worried about the issues listed than carers who provide support at a distance. For example, only 50% of carers who lived in the same home as the person they cared for were worried about hydration levels, compared with 63% of people who cared for someone at a distance. This is because people caring at a distance are less able to monitor and track what the person they care for is eating and drinking without suitable technology or monitoring in place.

“My child has food issues which worry me a lot. However, they are 17 and just moved into their own flat and so it’s up to them now. I have very little control. But I still worry. They don’t always make the best choices.”

“My daughter does not live with me. I have reduced influence on her eating healthily.”

We also looked at how various conditions affected how worried a carer is about different aspects of diet and nutrition, regardless of weight, but no significant differences were observed. We did, however, see differences in levels of worry when we looked at carers looking after people who were underweight and those who were overweight in the sections below.

Nearly half

47%



of carers worried about giving a balanced diet, rising to 59% of those caring for someone underweight

Eight out of ten

79%



of carers looking after someone underweight worry about how their condition affects diet and nutrition



Rapid weight changes

We asked all carers whether the person they cared for had either rapidly gained or lost weight. We found that 13% of all carers agreed that the person they cared for had rapidly lost weight and 14% agreed that the person they care for had gained weight rapidly. We discuss this further in the next chapters on caring for someone who is underweight and caring for someone who is overweight.



Only one in four

26%

of carers looking after someone who was underweight had advice from a dietitian.



Table 3: Where carers go for nutritional advice

Strongly agree or agree	All	Underweight	Overweight
None of these	27%	17%	28%
GP	13%	17%	13%
Nurse	9%	10%	9%
Dietitian	13%	26%	10%
Pharmacist	2%	3%	1%
A local voluntary group	1%	1%	1%
Online research	34%	28%	37%
Friend	5%	5%	6%
Family	8%	8%	8%
Another carer	3%	5%	3%
Other	10%	11%	9%

Where carers go for nutritional advice

Given the worry and anxiety faced by carers in diet, nutrition and hydration of the person that they care for, we asked where carers sought nutritional advice.

The most popular place for carers to go to for nutritional advice is online, with 34% of carers explaining that this is somewhere they get their information from. 13% of carers got advice about nutrition from a GP, but this was more likely if they were caring for someone who was underweight (17%). A significant number of carers also reported that they get their nutritional advice from somewhere not listed, and many carers shared that they have been able to use their own existing knowledge to make decisions on the diet and nutrition for the person they care for.

“ Seeing a paediatrician used to be excellent.”

“ I am already well qualified in this area myself.”

Men were more likely than women to seek out advice from all of the options given, with the only exception being that women were more likely to do their own online research. Black carers were also more likely to seek out advice from all the response options (other than from another carer) than White carers and were especially more likely than White carers to get advice on nutrition from their family members.

17%

of carers looking after someone who was underweight did not have advice from any sources



28%

of carers looking after someone who was overweight did not have advice from any sources



Identification of carers and advice from GP

The State of Caring 2021 survey also asked carers whether their GP knew they were a carer. The majority of carers (74%) reported that their GP knows that they are a carer, 8% said that their GP does not know that they are a carer, and 18% reported that they did not know whether or not their GP knows they are a carer.

Despite the majority of carers explaining that their GP knows they are a carer, only 13% had gone to their GP for nutritional advice. Only 7% of carers reported that their GP had arranged, talked to them about or suggested where they could go for information and advice to help them eat more healthily and only 5% reported that a GP had done this for the person they care for.

“ The advice given by GPs can be very hard to research and deploy in a practical manner. more detailed advice can be harder to access making the management of conditions harder.”

3. Caring for someone who is underweight

Under-nutrition and malnutrition are far more common than people may think and despite more resources having been developed, and efforts to try to raise the profile of this issue, awareness amongst professionals and families remains low. Much of under-nutrition or malnutrition is both preventable and treatable.

Good nutrition can increase healing abilities, improve mental health, cognition and wellbeing, energy, mobility, ability to fight off infection and more. Poor nutrition can result in infections which last longer, increased risk of falls amongst older and some disabled people, low energy – much of which leads to a negative health cycle.

When considering older people, a staggering one in 10 older people is estimated to be malnourished or at risk of malnutrition.¹⁵ Of the 11 million older people over the age of 65, around 1 million are in this group. They are a group where being underweight can easily be overlooked and they will not automatically receive advice in the way that someone having cancer treatment might, for example.

Evidence shows that malnutrition leads to an increased demand for support in acute NHS, community NHS and social care services. The latest cost analysis by BAPEN estimates that the cost of malnutrition to the health and social care systems was around £23 billion in the UK in 2011–12.¹⁶ Around half of the expenditure accounts for older people aged over 65 and the other half to younger adults and children.

The analysis by BAPEN has found that health and care costs for someone who is malnourished is two to three times more expensive than for someone who is not malnourished.



Interventions with nutritional support to implement the NICE clinical guidelines/quality standard, including oral nutrition supplements (ONS), enteral tube feeding (ETF) and parenteral nutrition (PN) in hospital and community settings, were found to lead to greater net cost savings than those reported by NICE.

The savings were even greater when the prevalence of malnutrition was high, when hospital admission rates were high, and when the gap between current care and desirable nutritional care was high.¹⁷ Given the pandemic, the increased pressure on health and care services, it makes even greater practical and economic sense to prevent under-nutrition.

The analysis by BAPEN has found that health and care costs for someone who is malnourished is two to three times more expensive than for someone who is not malnourished.

¹⁵ State of the Nation 2021 Older people and malnutrition in the UK today, Malnutrition Task Force, 2021 www.malnutritiontaskforce.org.uk/sites/default/files/2021-10/State%20of%20the%20Nation%202020%20F%20revise.pdf

¹⁶ The cost of malnutrition in England and potential cost savings from nutritional interventions (short version), M Elia, BAPEN, and the National Institute for Health Research Southampton Biomedical Research Centre, 2015 www.bapen.org.uk/pdfs/economic-report-short.pdf

¹⁷ Ibid.

Who are the carers looking after someone who is underweight?

Our State of Caring 2021 survey found that 14% of carers, or one in seven carers, were looking after someone who was underweight. This is a significant proportion of carers.

This group of people were more likely to be caring for a parent (45%, compared with 35% of all respondents) and unsurprisingly, someone who was older.

60% of respondents cared for someone between the age of 75-90, while just 46% of the total respondents cared for this age group. They were also the most likely to care for someone with dementia (36%), for someone who had needs that arise from being older (29%) and for someone who needs end of life or getting palliative care (6%). This means that measures and communications targeted at people who are older and with particular conditions is the right approach in terms of supporting unpaid carers.

However, 40% of carers looking after people who were underweight were caring for people who were younger – which means that tailored communications around condition and likelihood of caring, is critical.

Table 4: Carers' worries about diet, nutrition and hydration

Strongly agree or agree	Underweight
I worry about how to give a balanced diet to person being cared for	59%
I worry about how to manage their diet alongside their condition	68%
I worry about how their condition affects their diet and nutrition	79%
I worry that the treatments impact on their diet and nutrition	44%
I worry about the hydration of the person being cared for	72%

People caring for someone underweight in our survey were also less likely to live in the same home as the person they cared for and to be caring at a distance. 67% of people who cared for someone underweight lived with the person, compared to 77% of all respondents to this survey. This is an important issue for policy, advice and services.

Not living with the person being cared for can be more stressful and it can be very difficult to monitor nutritional intake. Mechanisms which support carers to feel more confident about nutritional intake when caring at a distance are essential.

Finally, people caring for someone underweight were also more likely to report that they cared for someone who lived in a care home, although the number of respondents is relatively low. While just 2% of total carers reported looking after someone in a care home, 4% of people caring for someone underweight reported that they lived in a care home.

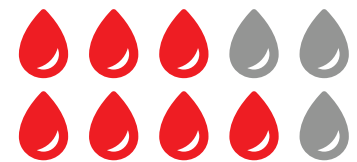
People caring for someone underweight were the most worried about the majority of issues regarding diet and nutrition. People caring for someone underweight were especially worried (up to 20% more than the other groups) about the hydration levels of the person they cared for.

Through previous research with carers we found that people on low incomes found it particularly difficult and stressful if the person they were caring for would decline food, especially if underweight. As they were on low incomes, there was additional stress around the extra cost, wasted food and money that they could not afford to spend. This is a particular worry now that the cost of living has increased for carers and their families.

“Good, healthy food costs money that we don't have.”

Seven in ten

72%



of carers looking after someone who is underweight also worry about hydration

Rapid weight changes

People caring for someone who was underweight were much more likely to have seen recent weight loss (50% compared to 13% of all respondents). This means that half of respondents were caring for someone who had a longer persisting condition of being underweight.

Rapid weight loss can be a source of significant worry and carers need to be able to spot this and manage the outcome with the right information, advice and medical intervention where appropriate. This means that people who were already at risk of malnutrition could be at severe risk.

Table 5: % of all carers who strongly agree or agree that the person they care for has lost weight rapidly

Weight category	Percentage
Underweight	50%
Overweight	16%
Healthy weight	29%
Don't know	4%
Total	100%

Half

50%

of carers looking after someone underweight had seen them lose weight rapidly



Where carers go for nutritional advice

Table 3 shows that carers of people who are underweight are much more likely to get medical advice of some kind. Carers of people who were underweight were most likely to get advice from a GP, a nurse or a pharmacist. They were also more likely to get advice from another carer. However, they were less likely to use the internet as a source of advice for nutritional information. While 34% of all respondents used the internet, only 28% of people caring for someone underweight did.

Carers looking after someone underweight were more likely to get their nutritional advice from a dietitian. One in four (26%) of people caring for someone underweight reported going to a dietitian, compared with 13% of all carers.

“She has stopped eating due to stress, I have taken advice from a dietitian on how to bulk up on the days she will eat. She is almost back up to a stable weight so I’m now switching to maintenance rather than increasing her weight”

11% of carers looking after someone who was underweight also reported that they get their nutritional advice from another source. Many carers commented here that this advice comes from specialist eating disorder clinics.

“My son was being seen twice a week in eating disorder clinic to ensure he ate breakfast, and to be weighed. This stopped during covid.”

Carers looking after someone who was underweight were most likely to go to one of the sources listed for nutritional advice. While 27% of total carers reported that they did not use any of the services, only 17% of people caring for someone underweight reported this.

“I feel I have a good knowledge of diet and nutrition and preparing meals and providing adequate nutrition is a key feature of my caring role. My husband lost weight due to illness but is back at a healthy weight now.”

Identification of carers by GPs and advice from GPs

Although people caring for someone underweight were more likely to go to a GP for nutritional advice, they were slightly less likely to report that their GP knows that they are a carer. Only 6% of people caring for someone underweight reported that their GP had arranged, talked to them about or suggested where they could go for information and advice to help them eat more healthily and only 6% reported that a GP had done this for the person they care for. Identification of unpaid carers by GPs should be a priority and could be particularly helpful when considering targeting information and advice about nutrition.



Conclusion and recommendations for carers of people who are underweight

Strategic planning and commissioning

Given the results set out in this report and considering work of others, it's clear that there is an opportunity for more strategic work to prevent under-nutrition in the community through clear leadership, updated commissioning guidance and with key health and care bodies taking a lead in ensuring support to enhance nutrition.

Information and advice for unpaid carers

The results show that whilst there is some medical intervention for people who are underweight, there is potential to ensure that this is enhanced. The high levels of rapid weight loss amongst people who are underweight is a concern and carers need the tools to be able to recognise this as well as be able to understand how to address it, including getting advice from a medical professional.

In terms of advice, the results show that for these groups, the internet is the most popular source of advice and there are particular groups for whom this could be more valuable. However, it is critical that advice is from trusted and reputable sources such as the NHS and well established patient groups. Raising awareness of what advice to look for is also essential, as under-nutrition in older people is less well recognised.

Accessible advice from medical professionals is key

Many easily accessible sources of healthcare advice, such as pharmacies, have only a limited knowledge in identifying and managing malnutrition. This should be improved through training to upskill these healthcare professionals so they can offer advice and support about malnutrition. Increasing awareness of appropriate resources that are available, such as leaflets, will enable people to more easily understand and access support for malnutrition.

The potential of digital and tech to help manage nutrition and hydration

Given that carers of people who are underweight are more likely to be living at a distance and worry significantly about them, assisted living technology is another tool along with wearable tech to help monitor nutrition and hydration, alongside input from any care services.

Shared care co-ordination apps like Jointly, can be used to monitor who is providing nutrition and hydration. Apps to monitor different diet and nutrition – where results can also be shared – can help track nutrition for carers who are worried.

Sources of advice on screening

The Patient's Association has developed some simple and easy to use resources to help identify malnutrition and take simple steps if discovered.

There are two versions of the checklist: one for use by patients and their families, and the other for health, social care and volunteers supporting them. The checklist helps to identify the risk of malnutrition in someone being cared for. The checklist offers advice on next steps and tips and ideas for eating such as contacting local organisations.

<https://www.patients-association.org.uk/patients-association-nutrition-checklist-toolkit>

Online self-screening tool for malnutrition – available to the public

This is a very simple public-facing validated tool developed by BAPEN to help non-health professionals who are worried about weight loss or low weight to see whether they are at risk of being malnourished.

This screening tool is based on the 'Malnutrition Universal Screening Tool' ('MUST'), a validated nutrition screening tool developed by BAPEN to help identify adults at risk of under-nutrition and the need for dietary advice. 'MUST' is the most common nutritional screening tool used by healthcare professionals throughout the UK. However, studies have shown that patients can screen themselves effectively using a simplified version of 'MUST' similar to the one provided here. If as carer has concerns they are advised to discuss them with their GP or healthcare professional.

All the carer needs to do is to enter current weight and height in the calculator and then enter the weight 3 – 6 months ago before illness or weight loss.

<https://www.malnutritionselfscreening.org/self-screening.html>



Sources of advice for carers on under-nutrition

Carers UK has a series of different downloadable leaflets about good nutrition, including eating well, understanding the nutrition gap and nutrition when caring for someone with a particular condition or disability such as dementia.

Carers UK also has practical advice on how to speak to your GP about nutrition and monitoring the nutritional intake of the person you care for so that carers are able to get a good objective record.

<https://www.carersuk.org/help-and-advice/your-health-and-wellbeing/the-importance-of-good-nutrition/>

Recommendations

Overarching recommendations relating to diet and nutrition

1. As diet and nutrition is a core part of people's wellbeing, it should be part of every health body's strategy to prevent ill-health and to challenge and tackle health inequalities. This strategy needs separate and dedicated approaches – one to tackle malnutrition and the other to support people who are overweight.
2. Care and carers' assessments under the Care Act 2014 (England) could be activated more to help with information, advice and support. These assessments include the statutory eligibility criterion: "ability to maintain nutrition", which provides a basis on which to ensure that there is appropriate tailored support. It is vital that people assessing unpaid carers or the people they are responsible for are able to understand the risks of under-nutrition as well as being overweight and ensure that the right information, advice and links are made with key health bodies or with community-based support.
3. To improve health outcomes, the use of patient and carer data needs to be maximised by flagging unpaid carers clearly on the patient's care record as well as the carers' own record to ensure that they are included and supported to help manage the nutrition of the person being cared for. This is particularly important where someone is at risk of malnutrition. It would also help to target proactive strategies to help people with weight loss.
4. Improve the knowledge and use of good quality internet-based information and advice as this is an important source for unpaid carers and provides an opportunity to maximise tailored support, particularly as a first step.
5. Ensure greater digital inclusion for people on low incomes or who are less confident about using the internet to ensure equality of access to this kind of information and advice, through local authorities, internet providers and health budgets where necessary.

6. Maintain traditional methods of information and advice i.e. face to face or via telephone, which remain critical for people not connected to the internet, or are necessary to gain a different perspective.

Specific recommendations to support carers of people who are underweight

These recommendations apply in principle to the whole of the UK, but we have referenced England related institutions or bodies in some specific recommendations.

Strategic planning and commissioning

7. A clinical lead for nutrition should be appointed within Government to manage the integration and implementation of policy on malnutrition into other strategic areas. Evidence suggests that tackling malnutrition could help to reduce admissions to hospital, reduce hospital stays, improve hospital discharge outcomes, improve recovery and reduce pressure on primary care services.¹⁸
8. NHS England to consider a refresh of the commissioning nutrition and hydration guidance published in 2015 to relate to the new Integrated Care Board (ICB)s' responsibilities and duties.¹⁹
9. Health bodies, e.g. in England, Integrated Care Boards and Integrated Care Partnerships (ICP), need to ensure that strategic planning engages all relevant parts of the Integrated Care System (ICS) a particular focus on preventing and treating under-nutrition. This should be directly linked to duties to reduce health inequalities and prevent ill-health.
10. Local health bodies should ensure that there is accessible information on preventing or treating under-nutrition which can be easily accessed, e.g. in pharmacies, GP practices, and in local charities which support disabled, ill, or older people or unpaid carers.

¹⁸ Guidance – Commissioning Excellent Nutrition and Hydration, NHS England, 2015 www.england.nhs.uk/wp-content/uploads/2015/10/nut-hyd-guid.pdf

¹⁹ Ibid

11. Local health bodies should ensure that planning, systems, awareness and support measures are appropriately accessible and tailored for unpaid carers and patients from Black, Asian and ethnic minorities and different faiths.
12. All local health systems need to adopt a systematic and preventative approach whereby:
 - All patients at risk are screened for malnutrition before transferring into a community or home setting.
 - Patient pathways include support for malnutrition within both the primary and secondary care settings.
 - Links between frailty and malnutrition are addressed with simple measures such as embedding the malnutrition risk score alongside frailty screening for the elderly.

Awareness

Awareness of under-nutrition needs to be increased as well as simple ways to identifying the condition, especially when it is preventable.

13. Every local health area, e.g. ICB in England, should have a rolling awareness programme which seeks to prevent malnutrition by encouraging widespread knowledge of the causes, symptoms and effects of malnutrition.
14. There should be a specific awareness raising programme with health and care staff around recognition and prevention.
15. Local carers' organisations should understand and be aware of the risks of under-nutrition and the importance of information, advice and support for unpaid carers.
16. Local carers' organisations should include regular information for carers on spotting the signs of malnutrition for people who are at risk of being underweight as well as simple ways to address this.
17. Health and care staff also should be raising awareness more broadly with unpaid carers about under-nutrition, ways to spot it and the steps to take if someone is at risk. This could include regular utilisation of tools such as the MUST online screening tool.²⁰

Support

18. Health and care systems need to provide unpaid carers with the practical support and interventions for the person they care for to be able to deal with under-nutrition or malnutrition with access to specialist advice.
19. Health systems need to provide specific support for unpaid carers who are on low incomes to prevent under-nutrition as well as effectively tackling malnutrition.
20. Health and care systems should promote the use of assisted living technology or off the shelf wearable tech to help carers who do not live with the person they care for to monitor nutrition and hydration levels and to raise awareness of the valuable role that this can play for carers in reducing anxiety.
21. Health and care systems should follow the Malnutrition Taskforce advice about to help prevent malnutrition.

²⁰ Malnutrition Universal Screening Tool www.bapen.org.uk/pdfs/must/must_full.pdf

4. Caring for someone who is overweight

There are several health risks associated with being overweight. For people with additional disabilities or illnesses this can add extra complications. Some people who are overweight can also be under-nourished when they don't get the right balance of nutrition.



During the pandemic many people put on weight with reduced opportunities for exercise, increased time at home, and poorer mental health and wellbeing. The Government has published updated policy designed to address the issue of being overweight.²¹ Public Health England led on this area, but responsibility has now moved to the Office of Health Improvement and Disparities in England. A new obesity strategy was launched in 2020 and was under review in 2022.

Whilst the 2020 strategy pledged targeted approaches to support disabled people who were overweight in the National Disability Strategy (NDS), this was not included in the final strategy when it was published in 2021. Given that it is more complicated for people with health conditions and disabilities as well as unpaid carers to maintain a healthy weight, targeted national measures could provide real opportunities for change.

²¹ Tackling obesity: empowering adults and children to live healthier lives, Department of Health and Social Care, July 2020 www.gov.uk/government/publications/tackling-obesity-government-strategy/tackling-obesity-empowering-adults-and-children-to-live-healthier-lives

Who are the carers looking after someone who is overweight?

Our State of Caring 2021 survey found that 39% of carers were looking after someone who was overweight. This is a significant number of people being cared for.

Nearly half were caring for their spouse or partner (45% compared with 37% of all respondents) who was overweight.

People caring for someone overweight cared for someone with a physical disability (53%), a mental health condition (37%), a combination of conditions and disabilities (33%), diabetes (19%) and asthma (12%).

People caring for someone overweight are also more likely to live with the person they care for (83%, compared with 77% of all carers).

Table 6: Carers' worries about diet, nutrition and hydration

Strongly agree or agree	Overweight
I worry about how to give a balanced diet to person being cared for	52%
I worry about how to manage their diet alongside their condition	59%
I worry about how their condition affects their diet and nutrition	69%
I worry that the treatments impact on their diet and nutrition	46%
I worry about the hydration of the person being cared for	51%

People caring for someone overweight were the most worried about how treatments affect the diet and nutrition of the person they care for (46%) compared with all carers (37%).

“Medication has caused weight gain and his ability to exercise is very limited due to pain and mobility issues.”



Like people caring for someone underweight, people caring for someone overweight were also most worried about the impact of the condition the person they cared for had on diet and nutrition, how to manage their diet alongside the condition, and how to provide a balanced diet for the person they cared for.

“Diet and exercise have a large impact on their condition. I have input a lot of time and effort, fortunately with good results according to the diabetes consultant. I do feel however that I can never relax my vigilance.”

People caring for someone overweight were also most likely to report that they agreed that they worried about not being able to afford to eat a healthy diet (29%) compared with all carers (21%). A staggering 57% of people caring for someone overweight reported they were struggling financially to make ends meet compared with 31% of all unpaid carers. This is an issue as healthier balanced diets can often cost more than processed and cheaper food that is high in fat or sugar.

Over half

57%



of people caring for someone overweight reported they were struggling financially



People caring for someone overweight were also more likely to report that they felt worried that they did not have enough time to create balanced meals for the person they care for (37%) compared with all carers (32%).

“Lack of opportunity, my time and their condition has impacted on the ability of the person I care for to exercise which has resulted in weight increase.”

“I would love to have more time to devote to healthy living.”

Rapid weight changes

Carers looking after someone who was overweight were more likely to say that they had gained weight rapidly (29% compared with 14% of all carers). People caring for someone overweight were also much more likely to report that COVID-19 restrictions had led to the person they care for gaining weight – 52% compared with 31% of all carers.

Carers and physical activity

We also asked carers about their levels of physical activity. We found a link between carers themselves being less active and reporting that the person they cared for was overweight.

While 49% of carers looking after someone of healthy weight reported that they were physically active (i.e. 2 or more hours of vigorous physical activity a week) only 35% of carers looking after someone who was overweight reported this same level of activity.

Where carers go for nutritional advice

Table 3 shows that people caring for someone overweight were the most likely to answer that they did not use any of the options listed to get their nutritional advice. Carers looking after someone overweight were slightly more likely to go to a friend for advice or through online research. 37% of carers of someone who was overweight used online research to get their nutritional advice compared with 34% of all carers.

9% of carers in this group also explained they get their nutritional advice from “other” sources, and many explained that this information comes from popular mainstream weight loss groups such as Weight Watchers and Slimming World.

“I get my nutritional advice online, and via my Slimming World group.”

Identification of carers by GP and advice

People caring for someone overweight were the most likely to report that their GP knew they were a carer (76%, compared with 74% of all respondents). 13% of carers who cared for someone overweight went to their GP for nutritional advice.

9% of carers of someone who was overweight explained that a GP had talked to them about or suggested where they could go for information and advice to help them be able to eat more healthily or manage weight, however only 6% reported a GP had done this in relation to the person they cared for.

Conclusion and recommendations for carers of people who are overweight

The results show that carers of people who are overweight have particular challenges which relate to their condition, but also their situation, including being on a low income. Caring for someone overweight can put additional pressure on carers' health particularly if the carer needs to move or lift the person being cared for. There is a need to improve advice and information about how a condition or treatments affect weight. Although Government strategies set out the overarching ambition, there is a real need to tailor this approach for carers of people with physical disabilities, mental illness and other conditions.

Carers UK is a keen supporter of the We Are Undefeatable campaign²² – seeking to increase physical activity for people with long term conditions and disabilities. It's a good example of understanding a tailored, positive approach, led by people with conditions. Carers UK also runs Carers Active, an initiative to help support carers to increase physical activity.

As well as key medical advice and intervention to support and explain weight gain and how to manage it, there is an important role for social prescribing in supporting carers and including options in outcomes of carers' assessments. This could include anything from physical activity sessions, wearable tech to monitor movement, and different support sessions for the person being cared for and/or the carer.

Carers Active

Carers Active is Carers UK's programme of work, supported by Sport England, aimed at promoting physical activity for carers.

Our research shows that carers providing significant amounts of care, i.e. over 50 hours of care, are less likely to be physically active.

Barriers include a lack of time, an inability to leave the house for some, tiredness, worry and cost. However, carers want to be healthier and fitter.

The level of carers' incomes, and the level of Carer's Allowance, the financial pressures faced by carers and their families makes this challenge much more difficult.



22 www.weareundefeatable.co.uk

Recommendations

Overarching recommendations relating to diet and nutrition

1. As diet and nutrition is a core part of people's wellbeing, it should be part of every health body's strategy to prevent ill-health and to challenge and tackle health inequalities. This strategy needs separate and dedicated approaches – one to tackle malnutrition and the other to support people who are overweight.
2. Care and carers' assessments under the Care Act 2014 (England) could be activated more to help with information, advice and support. These assessments include the statutory eligibility criterion: "ability to maintain nutrition", which provides a basis on which to ensure that there is appropriate tailored support. It is vital that people assessing unpaid carers or the people they are responsible for are able to understand the risks of under-nutrition as well as being overweight and ensure that the right information, advice and links are made with key health bodies or with community-based support.
3. To improve health outcomes, the use of patient and carer data needs to be maximised by flagging unpaid carers clearly on the patient's care record as well as the carers' own record to ensure that they are included and supported to help manage the nutrition of the person being cared for. This is particularly important where someone is at risk of malnutrition. It would also help to target proactive strategies to help people with weight loss.
4. Improve the knowledge and use of good quality internet-based information and advice as this is an important source for unpaid carers and provides an opportunity to maximise tailored support, particularly as a first step.
5. Ensure greater digital inclusion for people on low incomes or who are less confident about using the internet to ensure equality of access to this kind of information and advice, through local authorities, internet providers and health budgets where necessary.
6. Maintain traditional methods of information and advice i.e. face to face or via telephone, which remain critical for people not connected to the internet or are necessary to gain a different perspective.

Strategic planning and commissioning

7. A clear Government lead is needed on policies and actions to support people with disabilities and unpaid carers who are overweight, i.e. whole family approaches to tackle managing healthy weights with clear links to income, social care, specialist health advice for particular conditions and health prevention strategies.
8. The Office of Health Improvement and Disparities (OHID) should consider a programme of support for unpaid carers supporting people who are overweight.
9. Supporting carers needs to be a specific part of health bodies' delivery of reduction of health inequalities.
10. There should be a continued strategic support, by Sport England, for nationally led programmes such as We Are Undefeatable and Carers Active.
11. Locally set targets which systematically invite unpaid carers for health checks which include advice on nutrition.
12. Greater use of social prescribing and personal budgets to support carers' health and wellbeing as well as the people they care for.
13. Allow greater access to specialist advice and information when needed for carers, including health information related to particular disabilities.

Specific support for carers on low incomes:

14. Support for carers and their families on low incomes to be able to maintain a healthy diet and exercise.

5. Conclusion and recommendations

Diet, nutrition and hydration are key and constant worries for a large proportion of carers, regardless of the weight of the person they care for. There is a real opportunity to provide more information, advice and support to help carers deal with conditions that are both preventable and treatable.



With health and care services under pressure it makes strategic sense to ensure that malnutrition and under-nutrition are identified quickly and interventions put in to ensure that a person maintains a healthy weight. For carers, this reduces the amount of worry and concern on top of what can already be a stressful and challenging caring situation.

There are also long-term benefits in helping more disabled and older people maintain a healthy weight, along with their families.

The two areas, tackling malnutrition and supporting people who are overweight, each need strategic

leadership and planning from Government levels, through to regional and local health and care structures and delivery at the local level. Action needs to be specific, clear and targeted.

There is a real opportunity across the UK to engage health and care structures and systems which should ensure that there are robust commissioning arrangements in place to support nutrition and hydration, as well as supporting carers who are looking after people who are overweight. In England, this would include Integrated Care Systems (ICS) and in Scotland Health and Social Care Partnerships for example.

It is critical that ICBs in England ensure that there are robust commissioning arrangements in place for supporting nutrition and hydration, as well as identifying and supporting people who are malnourished and achieving better nutritional intake.

With approximately a third of all patients in hospitals or care homes with or at risk of malnutrition, there is a pressing need to improve malnutrition screening and management across all healthcare settings.

The integration of health and social care provides a significant opportunity to improve how malnutrition is identified and managed in England, as well as in Wales, Scotland and Northern Ireland, by ensuring that appropriate screening and support is available across the whole healthcare system, including in community settings.

By putting in place proactive strategies for the management of malnutrition, such as implementing the recommendations of endorsed guidelines such as the 'Malnutrition Pathway', health and care systems (e.g. Integrated Care Systems in England) would likely see significant clinical and health economic benefits.

With 93% of malnutrition estimated to be in the community, it is more important than ever that action is taken. Doing so have the potential to reduce pressure on healthcare services, and improve the health and quality of life of carers and the people they care for.

Our results also show that there are key equalities issues that need to be considered for carers from different ethnic minorities, people caring for others with different conditions, and significantly for carers on low incomes.

It's clear that there is a huge opportunity to tailor information, advice and support for unpaid carers. This could include supporting carers on low incomes, carers dealing with low mood and mental health or people facing the challenge of caring at a distance. Support clearly needs to be specifically targeted according to whether the carer is supporting someone who is underweight or overweight.

This needs to mobilise the whole community as potential routes to support. Using community support, facilities, mainstreaming through professionals and engaging key groups within the community are ways to ensure that carers are able to find the right kinds of information tailored to their situation. Given that Black and Asian carers are much more likely to consider nutrition advice within their own communities, community based approaches would be key to preventing under-nutrition in families. Social prescribing, personal health and care budgets and self-directed care offer more creative solutions in helping carers looking after people who are overweight.

Finally, there is a greater role for digital and tech across all groups in helping to:

- Promote tailored learning and understanding about diet and nutrition
- Manage weights, nutritional and hydration intake
- Provide group-based support – including supporting people who are underweight
- Identify carers and provide appropriate information

The health and economic value for interventions are clear, but in doing so, it would bring real and lasting benefits to unpaid carers and their families by improving health and wellbeing and reducing the levels of stress and caring.



Our results also show that there are key equalities issues that need to be considered for carers from different ethnic minorities, people caring for others with different conditions, and significantly for carers on low incomes.

Results for Scotland

Over 600 (616) unpaid carers in Scotland took part in the State of Caring 2021 survey.

82% of the Scottish respondents cared for over 35 hours a week and 51% cared for more than 90 hours a week. This level far outstrips the level of caring in the Census 2011 where 22% of carers provide over 50 hours of care per week.

Respondents to the survey were more likely to be female, with 84% identifying as female and 16% identifying as male.

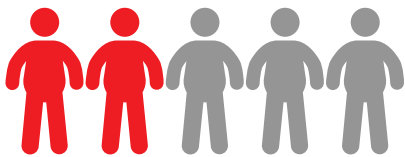
Nearly half of the carers who answered these questions cared for someone with a physical disability (46%) while 30% cared for someone with a mental health condition.

Who are they caring for in terms of weight?

Research evidence from the 2021 State of Caring survey found that while 44% of carers in Scotland care for someone considered to be a 'healthy weight', 37% care for someone overweight and 14% care for someone underweight. Only 5% of carers reported that they did not know whether the person they care for is overweight or underweight.

Two in five

37%



of carers in Scotland are caring for someone who is overweight

One in seven

14%



of carers in Scotland are caring for someone who is underweight



Characteristics of carers of people of healthy weight

Carers who reported their own health as “very good” or “good” were more likely to say that they were caring for someone of healthy weight. While 85% of carers with good health cared for someone of a healthy weight, only 57% of people who said their health was good cared for someone overweight and only 55% reported caring for someone underweight.

People caring for 90 hours or more a week were also most likely to care for someone considered a healthy weight (54%).

Carers who reported looking after someone of a healthy weight were also more likely to care for their son or daughter (44%).

Carers worry about diet, nutrition and hydration

Properly managing the diet and nutrition of the person you care for can be confusing, stressful and time-consuming. We asked carers to reflect on what worries them most about managing the diet of the person who they care for.

The table below highlights that the least significant worry for all carers is the impact that treatments have on the diet and nutrition of the person they care for. 31% of carers agree that this is something they worry about.

Carers of people who are underweight worry the most out of all carers about diet, nutrition and hydration.

The biggest worry for all respondent groups is how the condition of the person they care for affects their diet and nutrition. Carers of people who are underweight worry most about this (85%).

Table 7: Carers' worries about diet, nutrition and hydration in Scotland

Strongly agree or agree	Healthy weight	Underweight	Overweight	Don't know	All weights
I worry about how to give a balanced diet to person being cared for	40%	57%	53%	29%	47%
I worry about how to manage their diet alongside their condition	36%	65%	63%	35%	48%
I worry about how their condition affects their diet and nutrition	53%	85%	74%	59%	67%
I worry that the treatments impact on their diet and nutrition	27%	50%	46%	17%	31%
I worry about the hydration of the person being cared for	48%	67%	52%	56%	52%

Where carers go for advice

Table 8 shows that carers of people who are underweight are much more likely to get medical advice of some kind. While 31% of people who care for someone overweight said they do not use any of the advice sources listed only 7% of carers who look after someone underweight reported this.

Carers of people who were underweight were most likely to get advice from a GP, a nurse or a pharmacist. They were also more likely to get advice from a friend or a family member.

People caring for someone underweight were significantly less likely to use the internet as a source of advice for nutritional information.

While 32% of all respondents used the internet, only 26% of people caring for someone underweight did.

Carers looking after someone underweight were particularly more likely to get their nutritional advice from a dietitian, with 30% of people caring for someone underweight compared with 16% of all carers.

14% of carers looking after someone who was underweight also reported that they get their nutritional advice from another source. Many carers commented here that this advice comes from specialist eating disorder clinics.

Table 8: Where carers go for nutritional advice in Scotland

Strongly agree or agree	All	Underweight	Overweight
None of these	25%	7%	31%
GP	9%	12%	9%
Nurse	7%	9%	6%
Dietitian	16%	30%	9%
Pharmacist	1%	0%	1%
A local voluntary group	1%	0%	1%
Online research	32%	26%	37%
Friend	5%	7%	3%
Family	8%	11%	8%
Another carer	4%	4%	5%
Other	12%	14%	12%

Identification of carers and advice from GP

The State of Caring 2021 survey also asked carers in Scotland whether their GP knew they were a carer. The majority of carers (70%) reported that their GP knows that they are a carer, 9% said that their GP does not know that they are a carer, and 21% reported that they did not know whether or not their GP knows they are a carer.

Despite the majority of carers explaining that their GP knows they are a carer, only 9% had gone to their GP for nutritional advice. Only 5% of carers reported that their GP had arranged, talked to them about or suggested where they could go for information and advice to help them eat more healthily and just 9% reported that a GP had done this for the person they care for.

Results for Wales

740 unpaid carers in Wales took part in the State of Caring 2021 survey.

79% of the Welsh respondents cared for over 35 hours a week and 53% cared for more than 90 hours a week. This level far outstrips the level of caring in the Census 2021 where 22% of carers provide over 50 hours of care per week.

Respondents to the survey were more likely to be female, with 80% identifying as female and 17% identifying as male.

Nearly half of the carers who answered these questions cared for someone with a physical disability (48%) while 27% cared for someone with a mental health condition.

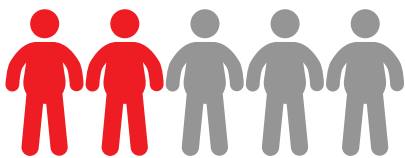
Who are they caring for in terms of weight?

Research evidence from the 2021 State of Caring survey found that while 40% of carers in Wales care for someone considered to be a 'healthy weight', 44% care for someone overweight and 14% care for someone underweight. Only 3% of carers reported that they did not know whether the person they care for is overweight or underweight.



Two in five

44%



of carers in Wales are caring for someone who is overweight

One in seven

14%



of carers in Wales are caring for someone who is underweight

Characteristics of carers of people of healthy weight

Carers who reported their own health as “very good” or “good” were more likely to say that they were caring for someone of healthy weight. While 50% of carers with good health cared for someone of a healthy weight, only 36% of people who said they health was good cared for someone overweight and only 12% reported caring for someone underweight.

Carers who reported looking after someone of a healthy weight were also more likely to care for their son or daughter (42%).

Carers worry about diet, nutrition and hydration

Properly managing the diet and nutrition of the person you care for can be confusing, stressful and time-consuming. We asked carers to reflect on what worries them most about managing the diet of the person who they care for.

Table 9 highlights that the least significant worry for all carers is the impact that treatments have on the diet and nutrition of the person they care for. 39% of carers agree that this is something they worry about.

Carers of people who are underweight worry the most out of all carers about diet, nutrition and

hydration. The only issue that people caring for someone underweight were less worried about was the impact of treatments on the diet and nutrition of the person they care for. While 38% of people caring for someone underweight reported this was a worry, 51% of people caring for someone overweight did.

The biggest worry for all respondent groups is how the condition of the person they care for affects their diet and nutrition. This worry is particularly prominent for people who care for someone underweight, with 73% of these carers agreeing that this is one of their worries.

Table 9: Carers' worries about diet, nutrition and hydration in Wales

Strongly agree or agree	Healthy weight	Underweight	Overweight	Don't know	All weights
I worry about how to give a balanced diet to person being cared for	36%	59%	50%	46%	45%
I worry about how to manage their diet alongside their condition	39%	62%	56%	50%	50%
I worry about how their condition affects their diet and nutrition	53%	73%	63%	69%	64%
I worry that the treatments impact on their diet and nutrition	27%	38%	51%	42%	39%
I worry about the hydration of the person being cared for	47%	66%	51%	43%	51%

Where carers go for advice

Table 10 shows that carers of people who are underweight are much more likely to get medical advice of some kind. While 32% of people who care for someone overweight said they do not use any of the advice sources listed, only 18% of people who look after someone underweight reported this.

Carers of people who were underweight were most likely to get advice from a GP or a pharmacist. They were also more likely to get advice from a family member or another carer.

People caring for someone underweight were significantly less likely to use the internet as a source of advice for nutritional information. While 32% of total carers reported using the internet, only 25% of people caring for someone underweight did.

Carers looking after someone underweight were particularly more likely to get their nutritional advice from a dietitian: 22% of people caring for someone underweight compared with 11% of all carers.

10% of carers looking after someone who was underweight also reported that they get their nutritional advice from another source.

Many carers commented here that this advice comes from specialist eating disorder clinics.

Table 10: Where carers go for nutritional advice in Wales

Strongly agree or agree	All	Underweight	Overweight
None of these	29%	18%	32%
GP	11%	18%	10%
Nurse	8%	7%	8%
Dietitian	11%	22%	10%
Pharmacist	1%	0%	1%
A local voluntary group	2%	3%	1%
Online research	32%	25%	33%
Friend	3%	2%	3%
Family	6%	9%	5%
Another carer	2%	9%	5%
Other	9%	10%	8%

Identification of carers and advice from GP

The State of Caring 2021 survey also asked carers in Wales whether their GP knew they were a carer. The majority of carers (68%) reported that their GP knows that they are a carer, 9% said that their GP does not know that they are a carer, and 22% reported that they did not know whether or not their GP knows they are a carer.

Despite the majority of carers explaining that their GP knows they are a carer, only 11% had gone to their GP for nutritional advice. Only 5% of carers reported that their GP had arranged, talked to them about or suggested where they could go for information and advice to help them eat more healthily and just 5% reported that a GP had done this for the person they care for.

Results for Northern Ireland

Almost 800 (776) unpaid carers in Northern Ireland took part in the State of Caring 2021 survey.

Almost three quarters (74%) of the respondents from Northern Ireland cared for over 35 hours a week and 51% cared for more than 90 hours a week. This level far outstrips the level of caring in the Census 2021 where 22% of carers provide over 50 hours of care per week.

Respondents to the survey were more likely to be female, with 82% identifying as female and 17% identifying as male.

Nearly half of the carers who answered these questions cared for someone with a physical disability (43%) while 26% cared for someone with a mental health condition.

Who are they caring for in terms of weight?

Research evidence from Carers UK's 2021 State of Caring survey found that while 47% of carers in Northern Ireland care for someone considered to be a 'healthy weight', 34% care for someone overweight and 14% care for someone underweight. Only 4% of carers reported that they did not know whether the person they care for is overweight or underweight.

One third

34%



of carers in Northern Ireland are caring for someone who is overweight

One in seven

14%



of carers in Northern Ireland are caring for someone who is underweight



Characteristics of carers of people of healthy weight

We looked at what whether there were any different characteristics for carers of people of healthy weight.

Carers who reported their own health as "very good" or "good" were more likely to say that they were caring for someone of healthy weight. While 36% of carers with good health cared for someone of a healthy weight, 29% of people who said their health was good cared for someone overweight and only 25% reported caring for someone underweight.

Carers who reported looking after someone of a healthy weight were also more likely to care for their son or daughter (45%).

Carers worry about diet, nutrition and hydration

Properly managing the diet and nutrition of the person you care for can be confusing, stressful and time-consuming. We asked carers to reflect on what worries them most about managing the diet of the person who they care for.

The table below highlights that the least significant worry for all carers is the impact that treatments have on the diet and nutrition of the person they care for. 19% of carers agree that this is something they worry about.

Carers of people who are underweight and overweight worry the most out of all carers about diet, nutrition and hydration.

While carers who look after someone underweight were the most worried about how treatments and hydration levels affect the people they cared for, people caring for someone overweight were most worried about how to provide the person they care for with a balanced diet and how to manage the diet of the person they cared for alongside their condition.

The biggest worry for most respondent groups is how the condition of the person they care for affects their diet and nutrition. This worry is particularly prominent for people who care for someone underweight, with 43% of these carers agreeing that this is one of their worries.

Table 11: Carers' worries about diet, nutrition and hydration in Northern Ireland

Strongly agree or agree	Healthy weight	Underweight	Overweight	Don't know	All weights
I worry about how to give a balanced diet to person being cared for	24%	27%	32%	28%	27%
I worry about how to manage their diet alongside their condition	22%	32%	33%	23%	27%
I worry about how their condition affects their diet and nutrition	26%	43%	36%	32%	32%
I worry that the treatments impact on their diet and nutrition	15%	24%	24%	15%	19%
I worry about the hydration of the person being cared for	24%	36%	27%	35%	27%

Where carers go for advice

Table 12 shows that carers of people who are underweight are much more likely to get medical advice of some kind. While 26% of people who care for someone overweight said they do not use any of the advice sources listed, only 16% of people who look after someone underweight reported this.

Carers of people who were underweight were most likely to get advice from a GP, nurse or a pharmacist. They were also more likely to get advice from another carer.

People caring for someone underweight were significantly less likely to use the internet as a source of advice for nutritional information. While 32% of total carers used the internet, only 18% of people caring for someone underweight did.

Carers looking after someone underweight were particularly more likely to get their nutritional advice from a dietitian: 28% of people caring for someone underweight compared with 17% of all carers.

12% of carers looking after someone who was underweight also reported that they get their nutritional advice from another source.

Many carers commented here that this advice comes from specialist eating disorder clinics.

Table 12: Where carers go for nutritional advice in Northern Ireland

Strongly agree or agree	All	Underweight	Overweight
None of these	27%	16%	26%
GP	14%	25%	13%
Nurse	6%	7%	5%
Dietitian	17%	28%	13%
Pharmacist	4%	7%	1%
A local voluntary group	2%	0%	2%
Online research	32%	18%	36%
Friend	7%	7%	8%
Family	10%	12%	12%
Another carer	3%	6%	3%
Other	9%	12%	10%

Identification of carers and advice from GP

The State of Caring 2021 survey also asked carers in Northern Ireland whether their GP knew they were a carer. The majority of carers (61%) reported that their GP knows that they are a carer, 13% said that their GP does not know that they are a carer, and 26% reported that they did not know whether or not their GP knows they are a carer.

Despite the majority of carers explaining that their GP knows they are a carer, only 14% had gone to their GP for nutritional advice. Only 4% of carers reported that their GP had arranged, talked to them about or suggested where they could go for information and advice to help them eat more healthily and just 4% reported that a GP had done this for the person they care for.

About this survey

This research was undertaken as part of Carers UK's State of Caring survey in 2021 which was undertaken as an online survey between August and September 2021.

A total of 8,676 carers and former carers responded to the survey – we have only included responses from the 8,119 people who are currently providing care in this report.

Compared to the carer population as a whole, respondents to this survey were more likely to be female and caring for a high number of hours every week. Of respondents to the survey:

- 72% live in England, 8% live in Scotland, 10% live in Northern Ireland, and 10% live in Wales.
- 79% identify as female, 19% identify as male and 0.5% describe their gender identity in another way.
- 28% consider themselves to have a disability.
- 3% are aged 0-34, 10% are aged 35-44, 23% are aged 45-54, 36% are aged 55- 64, 20% are aged 65-74, and 7% are aged 75 and over.
- 3% identified as lesbian, gay or bisexual.
- 4% described themselves as being part of an ethnic minority.
- 16% also have childcare responsibilities for a nondisabled child under 18.
- 34% are in paid work. Of those, 46% work full-time and 39% part-time.
- 33% have been caring for 15 years or more, 15% for between 10-14 years, 23% for 5-9 years, 26% for 1-4 years, and just 3% have been caring for less than one year.
- 48% care for 90 or more hours every week, while 14% care for 50-89 hours, 23% care for 20-49 hours, and 13% care for 1-19 hours a week.
- 76% care for one person, 18% care for two people, 4% for three people, and 2% care for four or more people.



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ISBN: 978-1-873747-68-1 | Publication code:UK4109_1222 | © Carers UK, March 2023

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