

Spotlight on...

Caring and nutrition



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Summary

Nutrition is an important but often hidden issue for carers and their families, with 60% of carers worrying about the nutrition of the person they care for.¹

People suffering from malnutrition are likely to experience a variety of health related problems which can increase their care needs.

The vast majority of people at risk of malnutrition live in the community, on their own, or with their families so making sure that carers have the advice and information they need about nutrition is a big issue for local communities.

This briefing provides a series of tools and resources that can be used to highlight nutrition and find solutions to improve nutrition, prevent malnutrition and boost health and wellbeing and support carers to care.



1 Carers UK (2012) Malnutrition and Caring, London: Carers UK

What is malnutrition?

Malnutrition can develop when someone does not eat enough food, or the correct balance of foods, to give their body the nutrients it needs.

This can affect their mood, growth, muscle strength, ability to fight infection, ability to recover from illness and many functions of the body.²

Malnourished people have:³

- More hospital admissions / readmissions
- Longer length of stay in hospital
- Greater healthcare needs in the community (more GP visits, care at home, antibiotics)

The clinical consequences of malnutrition are varied and include:⁴

- Impaired immune response
- Reduced muscle strength and frailty
- Impaired wound healing
- Impaired psycho-social function
- Increased falls risk
- Impaired recovery from illness and surgery
- Poorer clinical outcomes



2 Russell C, Elia M on behalf of BAPEN and collaborators. Nutrition Screening Surveys in Hospitals in the UK, 2007-2011: A report based on the amalgamated data from the four Nutrition

3 Stratton RJ et al. Disease-related malnutrition: an evidence-based approach to treatment. Oxford: CABI publishing; 2003.

4 Screening Week surveys undertaken by BAPEN in 2007, 2008, 2010 and 2011. 2014. <http://www.bapen.org.uk/pdfs/nsw/bapen-nsw-uk.pdf>. Accessed 10/03/17 and Stratton RJ et al. Disease-related malnutrition: an evidence-based approach to treatment. Oxford: CABI publishing; 2003.

Why is nutrition important?

Good nutrition can help the body to maintain and improve strength, support the response to medical treatment, improve wound healing and reduce infections. Good nutrition can help people to stay mobile and maintain their independence.*

What are the facts:

- More than 5 million people in the UK are either malnourished or at risk of malnutrition. Around 1.3 million of these people are aged over 65.⁵
- 93% of those at risk of malnutrition live in the community, in their own homes or with their family.⁶
- 74% of carers prepared all the meals of the person they care for.⁷
- 25% of carers providing substantial care look after someone who is underweight.⁸
- 55% of those being cared for, often around the clock, use nutritional supplements.⁹
- It costs more not to manage malnutrition than to manage it.¹⁰

As well as having a high personal cost for individuals, BAPEN has suggested that the public expenditure (in England alone) on malnutrition now stands at just over £19 billion per year, a rise of 50% in costs since the study was first completed in 2007.¹¹ BAPEN expects this cost to grow unless further action is taken to prevent malnutrition. The healthcare costs of managing individuals with malnutrition is three to four times greater than that of managing non-malnourished individuals, due to higher use of healthcare resources. The costs associated with malnutrition include: 65% more GP visits, 82% more hospital admissions, 30% longer hospital stays¹² as well as increased referrals to hospital, and increased admissions to care homes. In secondary care it increases complications in wound care, chest infections, pressure ulcers for example, increases length of hospital stay, readmissions, and so on.

* <https://www.webmd.boots.com/understanding-malnutrition/default.htm>

5 (Elia M, on behalf of the Malnutrition Action Group (BAPEN) and the National Institute for Health Research Southampton Biomedical Research Centre. The cost of malnutrition in England and potential cost savings from nutritional interventions (full report). 2015. <http://www.bapen.org.uk/pdfs/economic-report-full.pdf>)

6 Op cit

7 Carers UK (2012) op cit

8 Carers UK (2012) op cit

9 Carers UK (2012) op cit

10 (As ref 5)

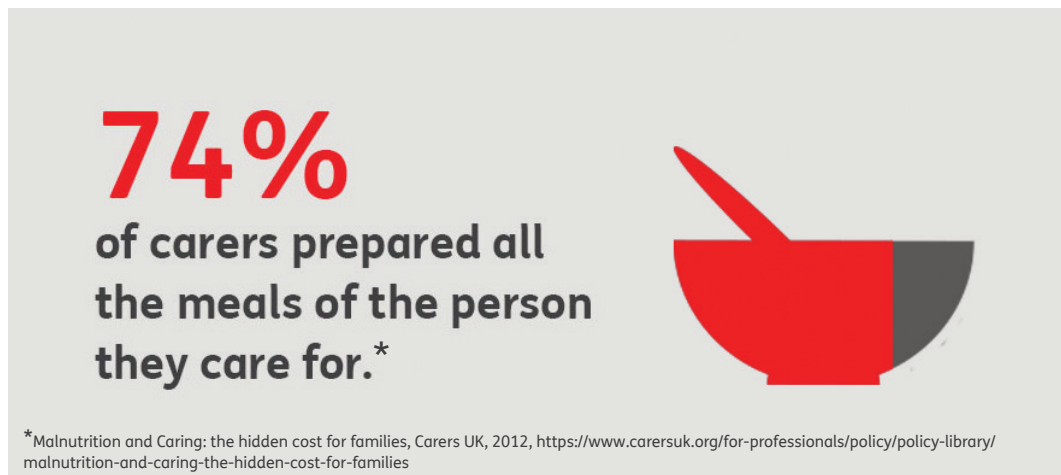
11 National Institute for Health Research Southampton Biomedical Research Centre (NIHR Southampton BRC) and the British Association for Parenteral and Enteral Nutrition (BAPEN), November 2015

12 Elia M and Russell CA (2009)

Why is nutrition for the person being cared for important to carers?

In 2012 Carers UK looked at carers' experiences of caring for someone who was malnourished or at risk of malnutrition. We found the following:

- High levels of self-reported stress
- Anxiety, frustration, feelings of failure and guilt that they are not doing enough
- Feeling that they cannot cope and have no control over their lives
- Dread around mealtimes, particularly if food goes uneaten and carers are on a low income.
- The need to provide extra levels of care as a direct consequence of malnutrition.
- Some carers talked about the large amounts of time it took to feed the person they were caring for.



Did you know...

Dementia affects the appetite as well as the ability to eat. Carers UK has some core information on dementia and what to do.

» [carersuk.org/dementia-and-nutrition](https://www.carersuk.org/dementia-and-nutrition)

Older people often have a smaller or suppressed appetite, particularly if they are unwell.

» [carersuk.org/improving-nutritional-intake](https://www.carersuk.org/improving-nutritional-intake)

Carers UK has a series of leaflets, developed in conjunction with Nutricia Advanced Medical Nutrition, which focus on particular conditions: cancer, dementia, swallowing problems, chronic obstructive airways disease and eating when older.

» [carersuk.org/nutrition-resources](https://www.carersuk.org/nutrition-resources)

Care Act 2014

The Care Act 2014 set a new landmark rights for both carers and the person needing care in terms of the way that it looks at nutrition. Decisions about whether someone is eligible for support are made around a set of criteria and these criteria are set out in the law.

Eligibility criteria for carers and the person needing care depend on whether the person needing care or carers need assistance with nutrition. This is in Section 2(a)(b) the person needing care has difficulties in managing or maintaining nutrition and for carers in section 3.2(b)(iv) carers are unable to manage or maintain their own nutrition because they are providing care and that this will have a significant risk on their own health and well-being.¹

Section 2 of the Care Act 2014 also looks at preventing the need for care and support from arising and any work to improve nutrition of either the carer or the person needing care, would fit well with this Local Authority duty and where the NHS has a duty to cooperate with the local authority to improve health and well-being.

What does “managing and maintaining nutrition” mean?

This is not just about going shopping, or planning a meal. It is where getting a balanced diet or sufficient nutrition makes an important difference to people’s lives. If someone needs additional assistance around nutrition, then that means they have eligible needs for support. Carers UK’s evidence is that carers need and welcome more information, support, advice and interventions to manage the nutritional needs of the person they are caring for as well as their own.

There are two areas where nutrition becomes important:

- The carer’s role in managing and maintaining the nutritional needs of the person who needs care and support
- The carer’s need to manage and maintain their own nutrition

25%
of carers providing
substantial care look
after someone
underweight*



*Malnutrition and Caring: the hidden cost for families, Carers UK, 2012 - the majority of carers in this survey were providing over 50 hours of care per week <https://www.carersuk.org/for-professionals/policy/policy-library/malnutrition-and-caring-the-hidden-cost-for-families>

1 Care Act 2014 <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

Do carers need help maintaining and managing their own nutrition?

There is strong research to show that carers can struggle with maintaining and managing their own nutrition because of caring. The evidence from carers is that they can often be pushed for time, and skip meals, under-eat or eat foods that are not balanced which could put them at risk of other long term health conditions.

Research evidence from Carers UK's 2013 State of Caring survey found that, where carers had significant caring responsibilities:

- A worrying 6 in 10 (58%) carers say they have neglected their own diet as a result of caring.
- When asked what they thought the reasons were for neglecting their own diets two thirds of carers (66%) said that they eat the wrong foods because they feel depressed.
- Nearly half (46%) said that they don't have time to prepare balanced meals and more than 1 in 4 (28%) said that lack of time meant they didn't eat enough.
- A third (34%) of carers said that they couldn't afford to eat a healthy diet.

We know that caring can take a heavy toll on the health of carers - 84% of carers surveyed told us that caring has had a negative impact on their health. Lack of time and the emotional impact of caring means that carers need extra support from health professionals to maintain their own health and wellbeing.

Carers' assessments and joint assessments are a good way to look at:

- Good advice around maintaining a healthy balanced diet for carers themselves.
- Advice for the carer around maintaining and managing the nutrition of the person they are caring for. Health professionals could provide key input into specialist advice for carers and local authorities have a responsibility to engage them in the delivery of the right outcomes for carers.
- Income maximisation for those carers who are most in need, so that they are more able to buy foods that promote a balanced diet.

NHS Health Checks are a good way to look at:

- Whether someone is caring, unpaid for someone else – systematically logging whether someone is a carer.
- Looking at improving diet to prevent a number of conditions and linking carers into the right advice about managing their own nutrition and that of the person being cared for.

Carers want information, advice and training

The majority of carers said they want more help and advice. 86% agreed with the statement: “We should be given more information about diet and nutrition early so that we can care for people better”.



Resources to help carers:

Online malnutrition self-screening tool for carers to use

There is a simple malnutrition self-screening tool (BAPEN, 2015) that carers can use for themselves or the person they care for in case they are worried about malnutrition. It also includes helpful advice that can be downloaded for carers. Or professionals could go through the tool with carers or as part of a group discussion exercise.

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

Carers UK free online learning course for carers on nutrition:

» carersuk.org/nutrition-elearning

This looks at carers learning about good nutrition, how to manage their own nutrition, how to look at the nutrition of the person being cared for, particularly if they are living with cancer, dementia or other conditions and what to do if food is not enough i.e. seek advice from a GP.

This online learning tool could be used as:

- Delivery on part of the outcomes from a carer’s assessment
- Part of improving health and well-being and prevention for public health
- A social prescription by GP practices or other organisations
- A training and learning tool for groupwork with carers together – discussing the contents and looking at what to change in their lives.

In terms of evaluation: 92% of learners found it useful for their situation. 79% found they learned something that they previously did not know and helped them to identify more information and what to do. Over 90% would recommend it to others.

Good practice: supporting carers locally with nutrition

Carers Network conducts carers' assessments for Westminster and Hammersmith and Fulham Councils. As part of the statutory assessment of carers they look at the carer's ability to "manage and maintain nutrition" in line with the Care Act eligibility criteria. They ask carers whether they find time to eat full and regular meals, eat healthily or whether there are financial constraints limiting this because of their caring role (for example if they had to give up work and are relying on limited money received from benefits). They look at whether the carer has time to shop and to cook, and whether they find this tiring, especially if they are the only one in the household doing this, or because the person they are looking after has a special diet owing to their health condition.

Carers Network said, "We encourage carers to think about their own health and acknowledge areas in which they are struggling and probably didn't think twice about before. Sometimes just having this conversation with the carer encourages them to start actively thinking about their health, and we explore ways in which it could be made easier for them, for example helping them to apply for funds towards a laptop so that they can do more online shopping, and in turn creating more time to do other things for themselves etc."

Carers Network also make referrals to other organisation such as the Health Trainers who also advise on diet and nutrition, and referrals are made to the social services if the carer would like help in their caring role, in turn creating more time for them to focus on themselves.

Listening and learning from carers' experiences

Several carers have told us their stories about how they balanced nutrition. You can see them here: Carole caring for her son with Sickle Cell Anemia, Lucia caring for her father with dementia, Margaret caring for her husband with dementia and Peter caring for his wife with MS.

» carersuk.org/help-and-advice/health/nutrition/carers-experiences

Ice Cold Chef

John Joyce is the husband of Bev, who has MS. After she found it difficult to cook, Bev taught John how to cook and he is now passionate about preparing tasty, low cost, nutritionally balanced meals that don't take a long time as he juggles work with caring for Bev. He and Bev are a team, recipes getting discussed between them. John is also known as the Ice Cold Chef and regularly posts blogs and videos and also does talks to local groups on how to manage cooking and caring.

<https://en-gb.facebook.com/IceColdChef/>

Taking action to improve nutrition:

Local authorities:

- Do your assessments of carers look at nutrition, beyond shopping and preparing meals, but their ability to stay healthy and well? Do your assessments look at their knowledge in relation to the nutrition of the person being cared for?
- After a carers' assessment, do you offer online resources and solutions in terms of managing good nutrition?
- Are you part of a local social prescribing network? Could learning around nutrition be supported through social prescribing?
- If you delegate carers assessments, does the organisation sufficiently explore nutrition with carers as part of assessments?

Public health:

- Does your work around prevention also include support for carers on areas related to nutrition?
- Does this cover the diabetes, stroke and heart disease prevention as well as positive nutrition for someone who struggles to eat or take in nutrition?

CCGs and GP practices:

- Do your commissioning arrangements also ensure that carers have access to specialist nutrition advice?
- Do local NHS Health checks regularly record whether someone is a carer? Do the checks link improving diet to resources and advice for managing nutrition and allow the carer to ask questions?

NHS Trusts – thinking about hospital discharge

- When looking at what support is needed by someone who will be discharged from hospital, do you include the carer in these discussions about how to manage nutrition in the community?
- Could you link them to some of these resources on social prescription?

NHS Trusts – how can Carer Passports help with nutrition?

A Carer Passport scheme identifies a carer, offers them a package of support and signposts them to information and advice. Existing Carer Passport schemes in hospitals are providing a range of benefits such as flexible visiting hours and discounted or free car parking. They also include measures to improve nutrition both for carers and patients, by including carers in refreshment rounds, providing discounts on meals purchased at the canteen and, crucially, by enabling carers to provide support for their loved ones during mealtimes.

Lister Hospital in Hertfordshire found that staff reported the Carer Passport scheme made a positive difference to patient nutrition as well as delivering other significant benefits for staff, patients, and carers.



Carer Passport

To find out more or learn about setting up a Carer Passport scheme visit:

www.carerpassport.uk

Local organisations providing support to carers:

- Do you regularly talk to carers about nutrition?
- Does your local public health agenda include areas for carers and nutrition?
- Does your local carer's assessment include questions on nutrition – and do they directly link into programmes that are useful for carers?
- Have you explored online learning for carers about nutrition?
- Could your local GP practices include carers' online learning on nutrition as a social prescription?
- Do you use regular group work to look at nutrition for carers, and nutrition of the person being cared for?
- Does the local authority commissioning arrangements, including their role within public health, look at supporting work around carers and nutrition – for themselves and the person for whom they care?
- Do your health and wellbeing events, such as activities during Carers Week, look at including advice on nutrition?
- Are there simple technology related responses which help carers' in their caring role? Everything from online learning and online resources through to simple equipment, there are things that can make a difference. Carers UK is working in partnership with social business Unforgettable, creating a marketplace of products to help carers. Many of these products relate to making mealtimes easier, from non-spill cups and bed trays to unobtrusive bibs to help preserve independence and dignity and make eating and drinking a more pleasurable experience. For more about a range of technology go here:
 - » carersuk.org/help-and-advice/technology-and-equipment

Spotlight series



Every day 6,000 people become carers, looking after family or friends who are older, disabled or seriously ill.

However caring affects you, we're here.

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For expert advice and information about caring, contact the Carers UK Adviceline.

T 0808 808 7777 E advice@carersuk.org

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