


Malnutrition and caring

The hidden cost for families





“You are watching someone disappear in front of your eyes. You just feel helpless.”

“You have another person’s life in your hands and you become the judge of what to do for the best.”

Over 2,000 carers told Carers UK about their experiences of managing someone’s diet and nutritional requirements. Each person’s story is unique, but they had so much in common. Through the lives of individual carers, this report details how carers cope with nutrition and the impact this has on their lives and those of the people they care for. We would like to thank all the carers who gave their time to tell their stories.



‘Care about nutrition, care with nutrition’ is a campaign by Carers UK and Nutricia to help carers through information and support on the importance of good nutrition and the benefits of medical nutrition.

Caring about nutrition

Getting the right nutrition from the food we eat is a basic requirement of life.

We take it for granted that we can get the nutrition we need from our diets. This gives us the strength and energy to go about our daily lives. But there are reasons why some people might not be able to eat properly or take in the nutrients they need – illness, disability and old age can all play a part.

For those caring for a relative or friend, the diet of that person is often the carer's responsibility. Three out of four carers we surveyed prepare meals for the person they look after. When things go wrong, their health and quality of life can suffer. For their carer it is distressing to watch a loved one lose weight and see their health deteriorate. Carers end up feeling anxious, guilty and not knowing where to turn. This should not happen and with the right advice and support, malnutrition is, in most cases both treatable and preventable.

Yet carers have not been part of the debate on tackling malnutrition. We need them to be centre stage and fully supported so they can provide the best possible care, which includes nutrition, for their loved ones.

Early identification of malnutrition and intervention will not only improve quality of life for individuals but release substantial cost savings for health and social care services.^{1,2,3} Implementing National Institute for Health and Clinical Excellence (NICE) guidelines on screening and nutritional support is estimated to provide the third biggest potential cost saving to the NHS.⁴

A clear focus on preventing malnutrition is therefore a 'win-win' for the patient, the carer and our increasingly stretched health service.

Malnutrition is a serious condition that occurs when a person's diet does not contain enough nutrients to meet the demands of their body. This can affect growth, physical health, mood, behaviour and many of the functions of the body.



Key points from this report about malnutrition:

- Malnutrition is a hidden issue in the community which needs to be urgently tackled
- Families are under stress and struggling to care without the right advice and support
- Malnutrition is largely preventable and treatable
- Earlier intervention will help to improve the quality of life for individuals and reap substantial cost savings to health and social care.

Related facts:

- More than 3 million people in the UK are either malnourished or at risk of malnutrition¹
- 93% of those individuals live in their own homes or with their family¹

Our survey found:

- 74% of carers prepare all the meals for the person they care for
- 25% care for someone who is underweight
- 60% of carers worry about the nutrition of the person they care for
- 55% of the people being cared for use nutritional supplements
- 16% were caring for someone who was underweight **and** with a small appetite **and** were worried about their diet **yet** were not having any nutritional support of any kind.

Devastating consequences



Maryann

At the age of 42, Maryann's mum, Carmel, had a brain haemorrhage that has left her with lasting brain damage.

Maryann now cares for her mum at home, as well as her own growing family, including twins aged 22 months, so she often has her hands full at meal times.

A few years ago Carmel started to have problems with eating and began losing weight. Maryann and her family understandably became very distressed. Maryann says: "This was so hard to cope with as a carer as you have another person's life in your hands and you become the judge of what to do for the best. To be honest I felt drained and it even seemed to be affecting my well being and mental state."

Maryann had the added worry of watching as her mother's health deteriorated. Maryann comments on her struggle, "My mum was becoming extremely withdrawn and didn't even have enough

energy to stay awake for more than an hour. I was also finding it extremely challenging to keep her fluid intake up."

Like many carers, Maryann found it difficult to find out about what help was available. "I could find no information on nutrition and until my mum had a home visit from a dietitian, I felt very alone in this crisis."

With the support and advice of a dietitian, her GP and hospital staff, Maryann was able to work out a system to help Carmel put on weight and regain some strength. Maryann says: "The additional nutrition Mum received really helped her to be as strong as she could be. Plus, as her appetite increased, her mood became more positive.

I think that I gained confidence once I managed to get Mum's body back up to a healthy stable weight. Before this I felt I wasn't doing it right and always felt I wasn't trying hard enough."

There are several reasons why a person may be at risk of becoming malnourished. They may not know about basic nutrition or be following healthy eating guidelines which may no longer be appropriate. They may have an underlying medical condition which impedes the absorption of nutrients. Disability or illness can also make eating difficult; for example people may have problems with swallowing, forgetfulness or lack of appetite because of illness or physical weakness.

The consequences of poor nutrition can be devastating for an individual. These include:

- vulnerability to infection
- delayed wound healing
- reduced muscle strength
- increased fatigue
- reduced mobility^{1,5}

These consequences are likely to increase the level of dependency someone has on their family or support services. As Maryann's example shows, the effects can also be devastating for the carer who feels worried, anxious and guilty.

Aside from the human cost there is also a cost to the public purse. Public expenditure on disease-related malnutrition in the UK in 2007 was estimated to be in excess of £13 billion per annum. This is considerably more than the cost of obesity.¹

Malnourished patients have increased healthcare costs with 65% more GP visits, 82% more hospital admissions and 30% longer hospital stays than patients without malnutrition.¹ They succumb to infection more often, and require longer-term care and more intensive nursing care.⁶

And yet substantial savings can be made through early recognition, for example using a screening tool such as the Malnutrition Universal Screening Tool ('MUST'),⁷ and then taking action to provide nutritional support such as dietary advice or the use of medical nutrition such as oral nutritional supplements.

Cost savings

£28,472 can be saved per 100,000 population if a nutritional screening programme was fully implemented, as recommended by the National Institute for Health and Clinical Excellence (NICE).^{4,8} It has been demonstrated that by implementing a nutritional screening and management programme that the documentation and use of appropriate care plans is much improved. In addition, healthcare costs can also be reduced through reduced hospital admissions and length of stay.⁹

"There is clear evidence that identifying and treating malnutrition keeps patients out of hospital, and improves quality of life. Clinical commissioning groups would do well to look at the longer term benefits of investment in appropriate nutritional screening and support for their vulnerable patients" Dr Tim Kimber, GP and Vice Chair of Coastal West Sussex Commissioning Federation

Struggling to care

Six out of ten carers worry about the nutritional intake of the person they look after.

Carers like Maryann, Pam and Gordon pay a heavy personal price struggling to care for someone who is malnourished. Carers experience:

- higher levels of self-reported stress
- anxiety, frustration, feelings of failure and guilt that they are not doing enough
- a feeling that they cannot cope and have no control over their lives
- dread around mealtimes, particularly when food is not eaten and carers are struggling on low incomes
- the need to provide extra levels of care as a direct consequence of malnutrition.

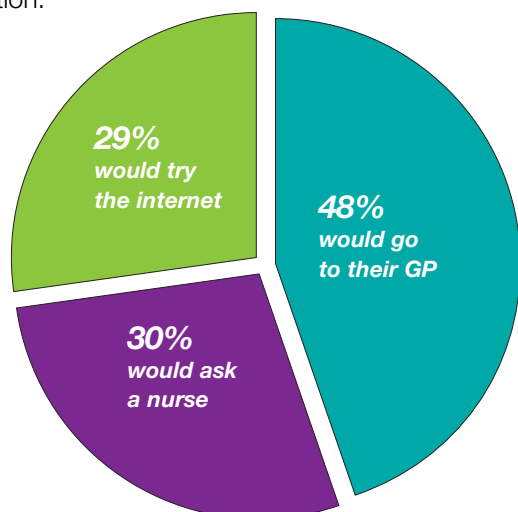
We know that the more care a carer provides, the more likely they are to suffer greater physical and mental ill health and are more likely to give up work to care. This means it is vital they get support and advice about nutrition to help them manage this crucial part of caring.

Carers always say that what they need is information and advice to do their job better. Whilst paid health professionals are trained to do their job, too often family members, who provide the bulk of care, receive little or no training, yet are expected to perform the same tasks. We would never ask a nurse to do their job without any training, but that is what is often asked of family members.

Sadly some carers felt let down by the very health professionals who we might expect to help them.

Liz, a carer for her grown-up autistic daughter feels “medical people don’t hold a lot of sway over diet”. Irene told us that she “campaigns vigorously and badgers the district nurses, dementia nurse and GP practice to get nutritional supplements prescribed”.

Our survey asked carers where they would go for advice on nutrition:



Pam

Pam is the main carer for her mother who had a stroke five years ago, and now suffers from dementia and depression. Her eating problems started when her dementia became more severe, and she stopped eating altogether.

Because Pam’s mother has very poor short term memory, she often forgets she has eaten, and this is hard for Pam to keep track of as they do not live together. “I find it really upsetting.” Pam said, “You are watching someone disappear in front of your eyes. You just feel helpless.”

Pam does not feel she has had proper help and support in dealing with her mother’s eating and nutrition. Her GP has not been very helpful and neither has the community

matron, who is supposed to keep her informed.

“I have also had problems with the careworkers, who often did not give my mother her medication or a hot meal, because they had not been given proper instructions.

It wasn’t their fault; they had not been told. I decided to do my own care plan and stuck it on the door of the cupboard where we keep Mum’s medication.”

“I think she has a reasonably balanced diet but because she eats very slowly, it is difficult to know if she always eats. I have found food hidden in kitchen roll – there is still a spark of rebellion there. If I had had more support I could encourage Mum to eat more.”

Gordon

Gordon is a carer for his wife Alice, who has a rare form of leukemia and fibromyalgia. Alice finds that her weight fluctuates and she struggles to eat foods which she previously enjoyed. Some foods cause digestive disturbances and pain, and it can be difficult for her and Gordon to identify and avoid them. Alice eats much less than she used to.

Gordon has found this very stressful to deal with. He discussed it with his GP and felt dismissed. “They said

that the dietitian was on holiday, and then that the practice didn’t have one at the moment, the previous one had left, and they hadn’t found anyone to replace them with yet. I felt fobbed off.”

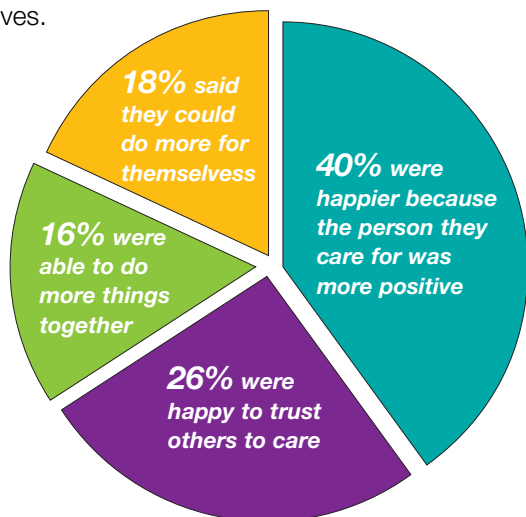
Gordon was diagnosed with depression two years ago and believes it is stress-related. When Alice was going through a phase of not eating, he said that he didn’t eat either. “I do find it very frustrating,” Gordon said, “I would just like to know why it is happening.”

Medical nutrition is scientifically formulated liquid food that is available in the form of a drink containing energy, protein, vitamins and minerals (also known as oral nutritional supplements) or delivered through a tube. This is used when nutritional needs cannot be met by diet alone and is often helpful for those living with a medical condition recovering from an illness or operation or those who have become weak and frail over time.

Transforming lives

These case studies (see boxes on right) show what is possible when carers get the right advice from nutrition experts and the right level of support at the right time. Carers and their loved ones should have access to high quality and understandable nutritional information about what constitutes eating well and how to provide a good nutritional intake. This should be available on the internet, in leaflets in surgeries, day centres and other places where people access information. In addition, carers should be told about what simple signs to look out for if the person the care for is not eating well and have easy access to a dietician, and get advice and support from their pharmacist or GP if concerned.

20% of respondents told us about the knock-on benefits of getting better nutrition for their loved one for their own quality of life. From their responses, 40% told us they were happier because the person they care for was more positive. 26% also said nutritional support meant they were happier and less worried when the person they cared for was receiving replacement care, allowing the carer to get a break from caring. 16% commented that improvements to the person's health meant the two of them were able to get out and do more things together and 18% said they were stronger so could do more for themselves.



Carers encountered difficulties in getting medical nutrition prescribed. Products such as oral nutritional supplements should not be used to replace a balanced diet for healthy individuals. However where someone is at high risk of malnutrition, dietary advice alone may not be sufficient. Research has shown that appropriate prescribing of oral nutritional supplements makes a significant difference to weight gain and health outcomes.¹⁰ Carers themselves confirm this. Over half of carers saw the benefits of increased weight gain and strength from the use of oral nutritional supplements by those they were caring for.



Sherry and Terry

Sherry and Terry both care for their 13 year old son William, who has cerebral palsy. William had a gastrostomy tube at only five weeks old, and the family feel well supported by doctors and dietitians. Mum Sherry says William has "grown and thrived, all on artificial nutrition."

With the advice and reassurance of medical professionals, Sherry feels confident that she has made decisions as a carer that have benefitted William's quality of life. When William was a newborn baby and a gastrostomy was proposed, Sherry was very

apprehensive about the procedure, but on reflection she realised that "the operation saved his life" and his artificial feeding has made his life less traumatic and more feasible for Sherry and Terry to care for William at home. Until three years ago, in addition to William's artificial feed, Sherry would give William breakfast, lunch and dinner. She and Terry would spend three hours a day feeding William as he'd reflux and bring food back up. Although it is "not the same as having a meal," feeding almost totally non-orally is "much more convenient" and less stressful for both William and Sherry and Terry.

Pete

Pete, 69, cares for wife Jill, 72, who has had several Transient Ischemic Attacks or "mini strokes" and has long suffered from depression too.

A couple of years ago Jill wasn't eating, she felt really nauseous, had an upset stomach and just couldn't face food. She began to lose weight. Pete had heard about oral nutritional supplements from other carers on the Carers UK

internet forum so he bought some at his local chemist. After Pete had bought them a couple of times, his pharmacist asked after his wife and informed Pete he could get them on prescription. Jill then got "great boxes of the stuff" prescribed and as Pete says, they were "marvellous, they really helped" as they got her over her sickness and back on to regular food.

What needs to change?

Malnutrition in the community is a hidden issue where problems can go undiagnosed for weeks, months and even years. Even if someone has a family member caring for them, they do not always know where to turn. Even when they do see their GP, they do not always get given the right advice.

Whilst the issue of malnutrition in hospital and care home settings has started to be taken seriously, malnutrition in the community is not being given the same prominence. Nutrition needs to be a core community and public health issue, giving families and friends the tools to provide the best nutrition possible from a healthy balanced diet to knowing where to turn if this does not appear enough.

Malnutrition through lack of appropriate care can be eradicated if there is a will to tackle its causes.

Change needs to happen at several levels:

- **Government** must recognise that malnutrition is a serious public health issue and make a commitment to end preventable malnutrition
- **NHS leaders** must reduce preventable malnutrition in the community
- **Health professionals** must support families better to help with identification of people who are malnourished or at risk of malnutrition and provide information to improve nutritional intake
- **Social care professionals** must learn to spot the signs of malnutrition

We want to see action on three key areas:

1 Supporting families to care

A significant proportion of carers are directly responsible for the nutrition of the person being cared for, or advocating on their behalf. As a consequence, carers must get the right information and advice about good nutrition.

Carers UK is calling for:

- Access to basic training and information on nutrition and recognising the signs of malnutrition must be made available for all carers who need it by 2015. This could be funded through collaboration between Government, Royal Colleges, expert organisations and industry.
- Access to experts who can support carers in giving good nutrition through existing healthcare channels and NHS Direct.
- Carers and their loved ones to be informed and consulted on options available to them, including both dietary advice and appropriate prescription of medical nutrition.
- All individuals identified at risk of malnutrition to receive adequate follow-up and care.

2 A Shift in priorities

As nutrition is fundamental to health, quality of life and dignity in care – it is a basic human right and needs to be made a greater priority.

To this end Carers UK is calling for:

- GPs or District Nurses to screen for risk of malnutrition at every appointment for vulnerable individuals.
- Screening for malnutrition and nutrition support must be made a **standard** part of care assessments, GP consultations, pharmacists' medicine review/consultations they may have on an ad hoc basis for requests for over the counter products or advice.
- Politicians, policy makers, budget holders, professional organisations, healthcare professionals and care workers must make prevention and management of malnutrition a high priority and treat it as seriously as any medicinal intervention.
- Families and carers must be listened to and their concerns addressed.
- Adequate resources must be allocated at a central and local level to tackle malnutrition.

3 A Joint National Strategy for malnutrition

We need a more strategic approach which ensures there is a consistent quality of nutritional care across the country and for it to be integrated into all care pathways.

Carers UK is calling for:

- A joint national strategy tackling malnutrition that spans public health and social care across all settings – including the community.
- Malnutrition to be incorporated into public health targets.
- A National Clinical Director for Malnutrition focusing on both the acute and the community setting.
- Government to have malnutrition as a priority that will deliver against all five domains in the Outcomes Frameworks targets.
- Quality standards for nutrition which includes malnutrition prevention and management should be developed that aligns across health and social care and is adopted fully.
- Quality standards for nutrition across health and social care which include malnutrition prevention and management.



CARERS UK the voice of carers

Carers UK is a charity set up to support the millions of people who care for an elderly relative, a sick partner or a disabled family member.

Carers UK

- supports carers and provides information and advice about caring
- influences policy through our research based on carers' real life experiences
- campaigns to make life better for carers.

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Nutricia specialises in the delivery of advanced medical nutrition for the very young, the old and the sick. As well as being the largest specialist nutrition company in Europe, Nutricia is the market leader in the UK.

Nutricia supply high quality feeds, systems and support services to patients and health care professionals. Through the Nutricia Homeward service, nutritional feeds, enteral feeding systems and nursing care can be delivered directly to patients' homes.

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