

# Managing Nutrition in Palliative Care

Information for patients, relatives and carers



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## Managing Nutrition in Palliative Care

Having or supporting someone with a terminal illness can be a very scary and daunting time. There are many care needs to consider for a person and it is important to get them right, one of those is nutrition and hydration (food and drink). This is usually a huge part of a person's life and can impact negatively during this time. It is important that the right advice and support is provided to hopefully reduce one of the many worries which can be experienced, and to avoid any misunderstanding about nutrition in palliative care.



## My/my loved ones' nutritional intake is worsening/ isn't improving, what is happening?

It's common for people with a terminal condition to have changes in the way they eat and drink, including having a reduced appetite, lack of interest in food or changes in taste. The person will also be deteriorating, becoming more fatigued and they may be experiencing increased symptoms of lack of hunger and nausea(feeling sick). This can happen even more so in the last few weeks and/or days of life. This is part of a normal process. As the body becomes weaker and slows down, people need and use less energy (calories), and therefore have less appetite. They may be less able to eat by themselves. As a result of these bodily processes, gradually weight loss also happens which again is a normal part of the process.



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## But, I feel like I need to do something to help!

It can be difficult to come to terms with. The person might feel upset or worried if they're not able to eat or are not interested in eating. It might also be difficult for family or friends; providing food and drink for our loved ones is a big part of showing that we care for them. Family and friends often want to continue doing this and worry that their loved one might be hungry or thirsty. There is something you can do to help.

## What can I do to help?

Family and friends can support a person with encouragement to eat and drink their favourite food and drink if and when they want them. But they shouldn't pressure the person into eating and drinking as they 'usually' would, but instead, they should offer food and drink on a regular basis, ensuring not to overwhelm the person with quantity. They should try nourishing fluids such as milky drinks or juices, which may reduce the



effort required from the person. You can also assist in eating and drinking if the person is unable to do so themselves. Make an individualised plan with the person of food and drink they enjoy and will be able to tolerate, while encouraging the person to be involved in the decisions about their food and drink. The person must be supported to eat and drink, with your assistance if required, for as long as they wish to do so. Good oral hygiene and mouth care practices should also be encouraged/provided on a regular basis.

## What should I be aiming for?

The main aim is to maximise and improve quality of life including comfort, symptom relief and enjoyment of food and drink. The calorie content of food and drink is not of prime importance because the aim of providing these foods is to reverse malnutrition and encourage weight gain.

However due to their condition, this is unlikely and will not increase a person's length of life. Weight loss is normal at this stage and quality of life is more important. Aggressive feeding can cause discomfort to the person and, distress and anxiety for all those involved. Family and friends often ask if their loved one can have artificial nutrition through the form of a prescribed oral nutritional supplement to increase calorie intake and weight. This is unlikely at this stage because there are little if any potential benefits in providing artificial nutrition.

In the last few days of life, the aim is to provide comfort and to offer mouth care and sips of fluids or mouthfuls of food as desired.

## Where can I get further support or information?

This leaflet has been provided to you by a registered healthcare professional who feels this advice is appropriate to you and your circumstances. However please discuss with them further if needed.

There may also be other healthcare professionals involved, such as your GP, specialist palliative care nurse and community nursing (district nurse) who can also be contacted to ensure physical and psychological care needs are being met and care is co-ordinated.

A person may also experience deterioration in swallowing function. If there are concerns about swallowing, please contact the person's GP for a referral to Speech and Language Therapy.

There are also a number of carers groups and online forums that can provide support such as Marie Curie Support Line, Sue Ryder Online Bereavement Community, Macmillan Cancer Support and the Carers Trust. Please ask your healthcare professional about accessing these services.





This document has been produced from the following resources:

- Marie Curie (2019) Eating and drinking problems
- PrescQIPP (2017) Guidelines for the appropriate prescribing of oral nutritional supplements for adults in primary care
- National Palliative and End of Life Care Partnership; Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020
- Leadership Alliance for the Care of Dying People (2014) One chance to get it right: Improving people's experience of care in the last few days and hours of life.
- National Institute of Health and Clinical Excellence Quality Standard (2017) Care of dying adults in the last days of life.

If you would like this in large print, braille or on audiotape or would like this document in an alternative language, please contact the Patient Advice and Liaison Service on 0800 015 4334.

#### Amharic

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#### Arabic

إذا أردت الحصول على هذه الوثيقة بالخط الكبير أو بلغة برايل أو على هيئة شريط صوتي أو مترجمة إلى لغة بديلة فيرجى الاتصال بخدمة التنسيق ونصيحة المرضى Patient Advice and Liaison Service على رقم الهاتف 0800 015 4334 .

#### Bengali

আপনি যদি এটা বড় অক্ষরের ছাপায়, ব্রেইল-এ, বা কোন শোনার টেইপ-এ পেতে চান অথবা আপনি যদি এই কাগজটা অন্য কোন ভাষায় পেতে চান, তাহলে দয়া করে 0800 015 4334 নম্বরে পেশেন্ট এ্যাড্‌লাইস এন্ড লিয়েজঁ সার্ভিসের সাথে যোগাযোগ করবেন।

#### Cantonese (traditional Chinese)

如果你希望本文件是采用大字印刷、盲文或录音磁带等格式，或者希望本文件是使用其它的语言，请联络病患建议与联络服务（Patient Advice and Liaison Service），电话号码：0800 015 4334。

#### Czech

Pokud byste chtěli dokument psaný většími písmeny, brailovým písmem nebo na zvukové kazetě nebo v jiném jazyku, prosím, kontaktujte poradenskou službu pacientům na tel. 0800 015 4334.

#### Farsi

در صورت تمایل به داشتن این سند به نسخه ای با چاپ درشت تر، به خط بریل یا نسخه صوتی، یا به زبانی دیگر، لطفاً با دفتر خدمات مشاوره و هماهنگی بیماران به شماره تلفن ۰۸۰۰۰۱۵۴۳۳ تماس حاصل نمایند.

#### French

Si vous désirez ce document en gros caractères, en braille, enregistré sur cassette audio ou dans une autre langue, veuillez contacter le service de conseils et liaison des patients (Patients Advice and Liaison Service) au 0800 015 4334.

#### Kurdish Sorani

ئێمگەر ئێهه زانیارییه به چاڵی گهواره، برایل، بۆ لاسهێنێ دنگی، دهخاوایێت بهخود ئێه به ئهنگێهه به به زانیاری دیکه دهخاوایێت، تکهیه پهیوهندی بکه به خزمهتگوزاری زانیاری و هاوئاهاهنگی ئهموخشهوه به ژماره 0800 015 4334.

#### Polish

Jezeli dokument wymagany jest w wersji drukowanej dużą czcionką lub alfabetem Braille'a, na kasecie audio lub w innym języku, prosimy o kontakt z zespołem ds. kontaktów z pacjentami (Patient Advice and Liaison Service) pod numerem telefonu 0800 015 4334.

#### Punjabi

ਜੇ ਤੁਸੀਂ ਇਸ ਨੂੰ ਵੱਡੀ ਛਪਾਈ, ਬ੍ਰੇਲ ਨਾਂ ਸੁਣਨ ਵਾਲੀ ਟੇਪ ਤੇ ਚੱਟੋਟੇ ਹੋ ਨਾਂ ਇਸ ਸਮਝਾਵਣ ਨੂੰ ਹੋਰ ਭਾਸ਼ਾ ਵਿੱਚ ਚੱਟੋਟੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਹਾਇਤਾ ਸੇਵਾ ਨਾਲੋਂ ਭਲੇ-ਮੇਲੇ ਸੇਵਾ (Patient Advice and Liaison Service) ਨਾਲ 0800 015 4334 ਤੇ ਸੰਪਰਕ ਕਰੋ।

#### Somali

Haddii aad jeclaan lahayd in aad kan ku hesho far waaweyn, farta braille ee dadka indhaha la' ama cajalad dhegeysi ah ama haddii aad jeclaan lahayd in aad dukumeentigan ku hesho luqad kale, fadlan Adeegga Talobixinta iyo Xiriirinta ee Bukaaneleyda (Patient Advice and Liaison Service) kala soo xiriir lambarka 0800 015 4334.

#### Turkish

Bu belgeyi büyük yazı, braille (kör alfabesi) veya ses kaydı olarak veya başka bir dilde almak istiyorsanız, lütfen 0800 015 4334 no.lu telefondan Hasta Danışmanlık ve İrtibat Hizmetleri ile bağlantıya geçiniz.

#### Urdu

اگر آپ یہ بری چھپائی، بریل میں یا صوتی ٹیپ پر حاصل کرنا چاہیں یا یہ دستاویز کسی قبول زبان میں چاہیں تو براۓ کرم پیسٹ ایڈوائس اینڈ لیاؤن سروس سے 0800 015 4334 پر رابطہ کریں۔

#### Vietnamese

Nếu muốn có tài liệu này dưới dạng in chữ cỡ lớn hơn, chữ nổi braille hay bằng ghi âm, hoặc bằng một ngôn ngữ khác, xin quý vị liên hệ bộ phận Dịch vụ Tư vấn và Liên lạc với Bệnh nhân theo số 0800 015 4334.

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