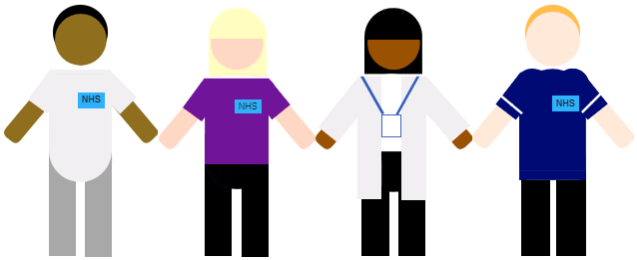
Oxford Health
NHS Foundation Trust

Staff guidance: Palliative care plan

Please use this guide to help patients complete their care plan



Community services

Palliative care plan

Palliative care is given to people with life-limiting conditions and helps them to live as well as they can for as long as they live.

The person may be on the GP's palliative care register (Gold Standards Framework). You can check on their medical records or discuss with their GP. They may be under a palliative care team at your local hospice.

If you think someone may be palliative and the above doesn't apply you can use the Supportive and Palliative Care Indicator Tool (SPICT) to help you decide and then liaise with their GP about adding the person to the Gold Standards Framework (GSF) register.

The SPICT tool helps to identify people with one or more advanced conditions for timely palliative care needs assessment and care planning. It is not a prognostic tool as people may deteriorate and die within very different time frames. It is care needs that are important rather than how long a person is thought to have left to live.

SPICT is supported by our Clinical Commissioning Group, available as an application and can be downloaded free from the application store.

Page one: what do you understand about your health condition?

The person may have discussed the progression of their illness with their medical team or GP. They may have forgotten some of those conversations or not taken them in at the time. They may ask you for more information and it will be helpful if you have looked at their notes or had a discussion with their GP.

They may not wish to discuss their condition and not want to carry on with the care plan. This is OK and just needs to be documented in your records. You can re-visit the care plan at a later date if appropriate.

Page one: if you are unable to communicate your wishes regarding your treatment and care

The person may not always be able to communicate due to loss of capacity. People may become muddled or confused as their illness progresses or they develop an infection. They may wish to choose someone they trust to speak for them.

If they have nominated an attorney for health and welfare (LPA) then you/they need to write their name on page one in the 'people important to you' section of the care plan.

Page one: do you have any of the following documents?

Do not attempt cardio pulmonary resuscitation (DNACPR)

This only relates to resuscitation should the person's heart stop or they stop breathing, not to any other treatment. Their GP, specialist nurse or community matron will discuss this in more depth with the patient and there is also written information available.

This document will be completed by the doctor, specialist nurse or community matron. It should be first discussed with the patient and those close to them (if appropriate). A copy should be kept in the patients home and taken with them if they go into hospital. It is for guidance only and is not legally binding.

Advance decision to refuse treatment (ADRT)

This is a legally binding document and refers to the refusal of medical treatment, for example if the person does not wish to have antibiotic therapy or cardiopulmonary resuscitation (CPR). The person can complete this document themselves or seek help from their GP. It must be signed, dated and witnessed. If it includes the refusal of CPR, words such as 'even if at risk to my life' must be included.

Advance statement

This is a statement that expresses the persons wishes. It is not legally binding but health professionals should follow it (if practical to do so). This care plan is an example of an advance statement.

Electronic proactive care plan (ePCP)

This plan is usually completed by the person's GP and records their preferred treatment options or ceilings of treatment and may include their preferred place of care. The GP will agree the care plan with the patient and complete it electronically; a copy is usually printed out and given to the person. The GP will share the information with Out of Hours GPs (111 service) and the ambulance service.

Lasting power of attorney (LPA)

LPA can only be made when the person has the capacity to make relevant decisions regarding their treatment and care. The nominated attorney can then make decisions in the person's best interests (as long as these are practical and achievable) once the person has lost their capacity.
The document has to be registered with the Office of Public Guardian.

Page two: what are your current needs, preferences, wishes, goals and choices?

These questions allow the person and their family to explore what is important to them from both a health and wellbeing perspective. For example their current health, whether they have pain or difficulty breathing: what concerns them most and what is more tolerable.

The person may want to reflect on their religious or other beliefs and important aspects of their life, such as food and drink preferences, types of clothes they like to wear, music preferences or whether they like a bath or a shower. They can say who they would like to visit them or be consulted about their care.

Do they have any goals that they want to achieve: small goals like improving their fatigue levels or mobility, getting out into the garden or going to the pub? They may have larger goals, such as moving house or getting married or there might be a particular event that they would like to attend.

They may wish to be referred to the hospice team for specialist symptom control, for example pain and other symptoms. They may be eligible to attend a day centre (offered by some hospices) or receive home visits.

Page 2: what matters most to you? Is there anything that worries or scares you that you would like to talk about.

Ask if they are worried or concerned about anything, e.g. what is happening to them/role change/loss of independence. Do they have unanswered questions or are they anxious about something else?

They may be worried about their spouse, partner or family and the effect their illness is having on them. They may be worried about physical symptoms, the purpose of them carrying on, guilt, remorse or the need to re-frame their goals.

Remember that physical symptoms and psychological and spiritual distress go hand in hand and improving any one aspect of their health may improve others; for example if they are less anxious they may also have less pain.

There may be a specific person known to the person they would like to talk to. If they would like to talk to a chaplain you can refer them to the spiritual care team within the trust.

Page 2: when decisions about your care and treatment need to be made is there anything you would like discuss? You may have a view about treatments that you would or would not want to have in the future

The person may currently receive interventions to help monitor or treat their health condition. It may be helpful to discuss the ongoing benefits of these interventions if they start to become less effective or become more burdensome. For example they may have blood tests or intravenous treatments that may need reviewing. You can discuss reviewing treatments with the person's GP or ask the GP to visit if necessary.

Page 2: **you may want to talk about what you want to happen if you became less well**, for example; your preferred place of care or concerns you may have about people close to you.

The person may wish to stay at home if they become more unwell or prefer to go into a hospice. It is important to advise, however, that a bed may not always be available.

Does the patient have any concerns about having care at home, such as the impact on their loved ones? Reassure them that we may be able to help them to stay at home by providing extra help from for example support visits from the district nursing service and Marie Curie night care. Additionally, they may be eligible for NHS funding to provide formal care.

It might be that the person has symptoms that are difficult to manage, such as pain or nausea and vomiting. Specialist palliative care teams will be able to help with these, either by visiting the person at home or perhaps through an inpatient stay at your local hospice. Ask the GP to consider a referral if appropriate.

Page 3: is there anything else you would like to talk about?

You can discuss any issues or concerns the person or family may have, including any difficulties in taking medication, whether their medication could be changed from tablet to liquid form or whether any of their medication can be stopped (in consultation with their GP).

The person may feel they would benefit from assistance with their personal care such as washing and dressing, showering and/or toileting or incontinence support. They may have an appliance such as a catheter or stoma bag that they need help to manage. You can help them by referring to social or NHS funded care for additional carer support.

The person or those important to them may worry that they have no appetite. They may have early satiety (feeling full quickly), anorexia (no appetite) or taste changes. Consider suggesting dietary changes: eating little and often/whatever they fancy and a diet high in nutrients.

They may be concerned about their finances. Are they worried about money or unsure whether they have all the benefits they are entitled to?

They may need help with travelling to appointments. If they do require assistance you can signpost them to organisations such as Age UK or you may be able to advise them yourself.

Page 3: other information, are any of the following in place?

Attendance Allowance or Personal Independence Allowance: The person may be able to get help with some of the extra costs caused by their long term or advanced condition. They can claim for this benefit if they require any help with their activities such as washing and dressing. They may be eligible for the higher rate if their condition is advanced and they have a limited life span or if they need help night and day. Their GP will need to complete a form called a DS1500 if they are thought to have a prognosis of 6 months or less.

Anticipatory medication: The GP may prescribe sub-cut *anticipatory medication* if the person is thought to be approaching the final stages of their life. You need to make sure that the medication is written up on the appropriate electronic Decision to Administer form (DTA). The medication can be kept somewhere safe until it is required. Teams such as the Hospital at Home team can visit overnight if necessary to administer the medication. See hospital at home section on page 13.

Day care

The person may require assistance with household tasks, personal care or other activities. Visits from a formal carer or a live in carer may assist them to maintain their independence and quality of life.

Funding

Formal care can be privately funded or funded through the council (social care) or the NHS depending on their condition and level of need.

The person/family may decline formal care and this should be respected and the family supported.

Night care

The person may require some help or support at night or if they have an informal carer they may require support and relief from caring.

If they would like help at night you can refer them to a night sitting service such as Marie Curie or local charity.

Marie Curie is a free service and partially funded by Oxford Health. It is coordinated locally by Continuing Health Care (CHC, central team). The service is run on a priority basis and can provide registered nurses and senior healthcare assistants to sit from 10pm until 6.30am. You can only request a sit for the forthcoming night. Some areas may also have help available from local charities.

Page three: are you registered as an organ/tissue donor?

If the person wants to donate their tissue after their death they will need to be on the NHS Organ donation register. It is very important that their family/close friend understand and support their decision because their support is needed for donation to go ahead.

Further advice and support details

Community nurse team

If person is are housebound a community (district) nurse will visit to take bloods or complete other health care tasks/carry out supportive visits.

Specialist palliative care team

The hospital may refer your patient to the community specialist palliative care team, based at your local hospice. A nurse will arrange to visit the patient at home and assist with any symptoms such as pain, breathlessness and psychological care.

Community Matron

If they need help with coordinating their care or your patient is complex you, your GP or other clinicians involved can make a referral to your local community matron. Their role overlaps with specialist nurse role.

Out of Hours

The Out of Hours (OOH) service provides medical support when the GP surgery is closed. A paramedic or doctor will come out to visit the patient during the evening or overnight if necessary.

Hospital at Home

The Hospital at Home team are available during the out of hour period (south, west and central regions). You need to request that your patient is added to their palliative list. Ideally the patient should have anticipatory medication available with an electronic DTA administration chart so that the clinician is able to assist patient with symptom control.

The team consists of nurses and paramedics who work alongside the GP OOHs service and provide care to known patients/those referred through OOHs.

Other

The person may have someone else involved in their care such as a charity or care provider. They may want to put their details on their care plan.

Concerns and complaints

We aim to provide you with a high quality service at all times. However, if you have any concerns, complaints or comments about your experience of our service then please tell a member of the team or contact the Patient Advice and Liaison Service on freephone 0800 328 7971.

Notes

If you need the information in another language or format please ask us

Nëse ky informacion ju nevojitet në një gjuhë apo format tjetër, ju lutem na kontaktoni

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اگر آپ کو یہ معلومات کسی دوسری زبان میں یا کسی دوسرے طریقہ سے درکار ہوں تو برائے مہربانی ہم سے پوچھیں۔۔

Oxford Health NHS Foundation Trust
Trust Headquarters
Warneford Hospital
Warneford Lane
Headington
Oxford, OX3 7JX

Switchboard 01865 901 000
Email enquiries@oxfordhealth.nhs.uk
Website www.oxfordhealth.nhs.uk

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