PALLIATIVE CARE

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PALLIATIVE CARE

Introduction

Palliative care is the active holistic care of residents with advanced progressive illness. Palliative care was previously used as the only option for a resident when active treatment had failed. Palliative care can now be used in combination with disease modifying or curative treatments. It is an approach, which has the aim of improving the quality of life of residents facing the issues associated with life threatening illness.

Palliative care provides comprehensive treatment for the discomfort, symptoms and stress of serious illness. This is achieved through the relief, as much as is reasonably practical, of suffering by means of the early identification, assessment, and treatment of pain and other issues, whether physical, psychosocial, and spiritual. This policy reflects the requirements of Sunlight Cares for Older People National Care Standards.

Aim

Sunlight Care's aim is to maintain, and as far as possible, improve the quality of life of residents with progressive or life limiting illnesses, and to support those closest to them. It is vitally important that each resident is recognised and respected as an individual and that their particular care needs are assessed, recognised, and met with care and compassion.

Guiding Principles

Sunlight Care is committed to the provision of consistently high-quality palliative care.

Sunlight Care aims to:

1. enhance the resident's quality of life
2. control any pain or other symptoms well
3. adopt a person-centred holistic approach to planning care, taking into account the resident's life experience and current situation
4. plan and deliver care in close consultation with the resident and those closest to the resident
5. respect the resident's own choices, about how he or she wishes to spend their final days
6. communicate with the resident and those closest to them openly and sensitively
7. help the resident to deal with emotional and spiritual matters
8. support families and friends throughout the illness of a loved one and in bereavement

Palliative Care Approach

This is an approach to caring for residents as individuals, which recognises the importance of good communication and the importance of respect for individual autonomy and dignity. It recognises the resident's needs, which may be physical, social, psychological, or spiritual, or a combination of these.

Palliative care provides relief from distressing symptoms including pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, and problems with sleep. It can also help to deal with the side effects of medical treatment administered. Perhaps, most importantly, palliative

care can help improve a resident's quality of life.

End of life Care
The General Medical Council considers a resident to be approaching the end of life when they are likely to die within the next 12 months. This includes a resident who is expected to die within the next few hours or days, as well as those with advanced incurable conditions.

It can also include residents who have:

- general frailty and co-existing conditions which mean they are likely to die within 12 months
- existing conditions, if they are at risk of dying from a sudden crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events, such as an accident or a stroke.

End of life care may last a few days, or for months or years, beginning and ending when it is needed.

End of life care provides support for any resident who is approaching death. It helps that resident to live as well as possible until they die, and to die with dignity. It also provides support for their family or carers.

The principles which apply are:

- the use of informative, timely and sensitive communication, being an essential component of each individual resident's care
- the making of significant decisions about a resident's care, including diagnosing dying, which decisions are made on the basis and outcome of multi-disciplinary discussions
- the recognition of each individual resident's physical, psychological, social and spiritual needs, which will be addressed as far as is possible
- consideration of the wellbeing of the relatives of the resident.

Advance Statement
An Advance Statement is a written statement, which sets out a resident's, preferences, wishes, beliefs, and values regarding their future care.

The aim is to provide a guide to anyone who might have to make decisions in the resident's best interests if, after making the statement, the resident loses the capacity to make decisions for themselves or loses the ability to communicate their decisions.

An Advance Statement can cover any aspect of the resident's future health or social care. This could include:

- how any of the resident's religious or spiritual beliefs should be reflected in their care
- what their preferences are, for example, if they prefer a shower instead of a bath, or like to sleep with the light on

By writing an Advance Statement down, the resident can help to make things clear to their family, carers and generally anyone involved in their care.

Advance Decision
An Advance Decision is a decision which sets out clearly the forms of treatment which a resident makes to refuse a specific type of treatment at some time in the future and is legally binding.

It lets family, carers, and health professionals know whether the resident wants to refuse specific treatments in the future. This is so that they will know the resident's wishes if he or she is unable to make or communicate those decisions.

The treatments, which the resident wishes to refuse, must all be specified and set out clearly in the advance decision.

Sometimes, the resident may want to refuse a treatment in some situations but not others. If that is the case, all the circumstances in which they want to refuse the treatment must be set out and recorded clearly.

An Advance Decision can be made, as long as the resident has the mental capacity to make such decisions. The resident may want to make an advance decision with the support of a clinician. The resident can refuse life sustaining treatment, such as ventilation and cardiopulmonary resuscitation.

Each Advance Decision must be:
- written down
- signed by the resident
- signed by a witness

The Advance Decision is legally binding if it:
- complies with the Adults with Incapacity Act
- is validly signed
- applies to the situation

If the Advance Decision is binding, it takes the place of other decisions made in the resident's best interest by other people.

An Advance Decision may only be considered valid if:
- the resident is aged 18 or over and had the capacity to make, understand and communicate the decision when it was made
- the treatments which are being refused are clearly specified
- the circumstances in which the resident wishes to refuse the treatments have been fully explained
- it is signed by the resident and by a witness
- the advance decision has been made of the resident's own accord, without any harassment or influence from anyone else
- the resident has not said or done anything which would contradict the advance decision since it was made

Welfare Power of Attorney
If it is their wish, and the resident has the necessary capacity to make this decision, the resident can officially appoint someone they trust to make decisions for them.

This is called making a welfare power of attorney. This enables the resident to give another person the right to make decisions about their care and welfare. The resident can also appoint an attorney to decide on financial and property matters, and this is generally known as a Financial Power of Attorney.

If the resident becomes unable to make decisions, and it is considered necessary that someone will need to make decisions on their behalf, an application can be made to the Office of the Public Guardian to appoint a Welfare Attorney and/or a Financial Attorney. Who does this will depend on the facts and circumstances that apply at the time. Generally, professionals will make decisions about health and social care, and family or carers will decide on day-to-day matters.

Assessment of the Need for and Implementation of Palliative Care
Where a resident has a diagnosis of an advanced progressive illness, a Palliative Care Assessment and Care Plan will be developed in discussion with the resident and those closest to them.

Sunlight Care recognises it is important to help the resident and those closest to them understand the nature of the illness and the expected prognosis.

Care Plan
Symptomatic relief, where possible, is the main priority in providing effective palliative care. Symptoms, which must be addressed, can include pain, agitation, breathing difficulties, respiratory tract secretions, emotional and psychological issues, difficulty with communication, pressure areas and pressure sores, nausea, insufficient dietary intake, poor fluid intake, oral hygiene, bladder dysfunction, bowel dysfunction, and any other symptom relating to the treatment of the illness itself.

Sunlight Care will endeavour to alleviate, and where possible improve any issues the resident has.

Access to Specialist Palliative Care Support and Advice
Specialist palliative care is provided by the multi-professional palliative care teams and can be accessed by the resident's General Practitioner. Specialist palliative care nurses are experienced in assessing and treating symptoms and also can provide counselling and emotional support for the resident and those closest to them.

Most specialist palliative care nurses work closely with a wider hospital or community palliative care team, which includes doctors and other healthcare professionals.

Specialist services such as psychiatry, speech and language, dietician, and clinical nurse specialists, should be consulted where this could be beneficial for the resident and the plan of care.

Equipment
All equipment necessary to ensure the comfort of the resident will either be available in Sunlight Care or accessible from the community.

Basic equipment such as electric fans, pressure relieving equipment, and recliner chairs are available in Sunlight Care.

Portable nebulisers, syringe drivers, and suction machines can be accessed by contacting the district nurse.

Cardio-Pulmonary Resuscitation
Sunlight Care understands the importance of having open communication between the resident, those closest to them and health professionals.

Cardio-pulmonary resuscitation (CPR) can be attempted on any individual in whom cardiac or respiratory function ceases. It is essential to identify residents for whom CPR will not work and/or is inappropriate.

It is essential to discuss the subject of whether the resident wishes CPR to be attempted in the event of an arrest, and who competently can make a decision whether or not to have that treatment option.

These statements must be respected as long as the decisions are informed, current and are made without coercion or undue influence from others.

Where residents are acutely unwell or become medically unstable in Sunlight Care their resuscitation status will be considered as soon as is reasonably possible. If a resident is not competent to make this decision, then the medical team must decide the best option in consultation with those closest to them.

Families should never be placed in a position that they feel they are making a DNAR decision unless they are the legally appointed guardian or attorney for the resident.

End of Life
Residents approaching the end of life are offered comprehensive assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

Assessment
It is essential to identify any causes for the resident's deterioration.
These may include:

- dehydration
- infection
- drug induced toxicity
- steroid withdrawal
- acute

- kidney failure
- delirium
- hypercalcaemia
- hypo or hyperglycaemia

Treatment should be commenced, if appropriate for the individual resident and if appropriate to the care setting with regular reviews. Discussion at this time may include appropriate levels of intervention.

The prognosis should be considered and discussed with the resident, or a welfare attorney, and the family. The aims of care should also be agreed with them.

Account should be taken of any Advance Statement and any Advance Decision made by the resident and anticipatory care planning. An individual care plan will be agreed with the resident, if possible, or any welfare attorney, or guardian and shall be discussed with the family, and documented. This includes a decision about cardiopulmonary resuscitation.

Management
Regular planned review and consideration of the care plan will make sure the best care is given as the resident's condition deteriorates, stabilises or improves. The steps taken will include assessment of the following:
Food and drinks: providing support or assistance in helping the resident to eat and take fluids
Comfort care: considering the use of an alternating pressure mattress to minimise avoidable skin breakdown due to overall deterioration of the resident's condition, repositioning the resident for comfort, providing eye care, mouth care, bladder and bowel care.

Medicines: reviewing and consulting with healthcare professionals about the prescribed medication and treatments. If the resident is having difficulty swallowing consult the doctor regarding considering changing to liquid formulations, or where necessary consider the need for a subcutaneous infusion of medication via a syringe pump. In addition, it is important to make sure anticipatory medications for common symptoms are available and prescribed for as required use, by oral and subcutaneous routes.

Investigations or clinical interventions: considering, and regularly reviewing, the appropriateness, benefit and any negative impact on the resident of the carrying out of blood tests, radiology and other procedures.
A clear record of any interventions that are not appropriate should be made.

Assisted hydration or nutrition: considering the benefits and risks and reviewing the care plan regularly.
Over-hydration can contribute to distressing respiratory secretions. However, where indicated, a slow subcutaneous fluid infusion may be considered on an individual basis.

Consideration: taking account of the emotional, spiritual, religious, cultural, and family needs.

Bereavement: identifying those who will need support.

Family members are encouraged, where possible, to take an active role in the care of their loved one, and the resident's family can if they wish, play an active role in, hydration, feeding, reducing risk of pressure sores, and relieving anxiety and pain.

This can be extremely beneficial to all involved.

It is important that both the resident and relatives are given privacy as required.

Communication
Discuss the care plan with the resident, if possible, and the family, and explain what changes to expect in the resident's condition.

Make sure family members are aware of the care plan. Record a plan of how and when to contact the family if the resident deteriorates or dies.

Anticipatory Prescribing
All residents should have as required medication, prescribed by the General Practitioner for symptom control available.

- Pain
- Agitation or Delirium
- Nausea and vomiting
- Breathlessness
- Intermittent breathlessness or respiratory distress
- Persistent breathlessness or respiratory distress
- Respiratory tract secretions

In a sensitive manner, the resident will be encouraged to discuss their wishes for the end of life. It is vitally important that each resident is given the opportunity to clearly state what they would like to happen, including any preferred funeral arrangements.

They will also be encouraged to discuss any social, cultural, faith, and lifestyle preferences they have, and these will be clearly detailed in the care plan. Where possible, arrangements will be made to support the resident in their chosen culture, faith, belief, and lifestyle.

Counselling
A terminal diagnosis, and palliative care can bring up anxieties, worries and fears, and it can be of benefit to talk about these. Family members and friends will be dealing with their own feelings about the diagnosis. In the days and weeks prior to someone dying, sharing feelings and fears is important, as that helps to build trust and mutual confidence.

It can be helpful for some to talk to a counsellor. Counsellors are trained to help people in all types of situations and seeing a counsellor can help people to understand and express their feelings, and cope better with their situation.

Relatives
Provision will be made for relatives or friends to be accommodated overnight in Sunlight Care in order that they can be with their loved one at the end of their life, if that is their wish.

Training
All staff will be given training on the subject of palliative care, loss, death and bereavement. They will have a clear understanding of what is meant by palliative care and end of life care. They will be aware of the palliative care approach and use this approach when looking after residents with life-limiting illnesses. They will understand how to get help and advice in providing general palliative care and recognise when this is required. They will understand how to access specialist palliative care advice and specialised services where appropriate.

They will be familiar with the terms of this policy, the policy on resuscitation, and the policy on end of life care. Sunlight Care has a copy of the NHS policy on DNACPR, of which staff will be made aware as part of their training. The staff will be given training on the procedures that need to be followed for last offices. These policies are subject to review not less than once each year and staff will be made aware of all policy changes as soon as is reasonably practical after they are made.

All staff who have been involved with the resident and their end of life care will be encouraged to reflect on their practice on an ongoing basis, and where necessary counselling can be arranged. Records of the training provided will be kept and refresher courses will be undertaken annually.

Audit
It is important to regularly assess and audit the delivery of palliative care. This ensures that it continues to be extremely person centred, compassionate, effective, and delivered to the highest standard possible.

This is achieved through the palliative care assessment and feedback from anyone who has an involvement in the provision and the receipt of the palliative care.