

The Leicester, Leicestershire and Rutland

Making Choices Handbook

For Adults with Learning Disabilities

This Belongs To:

.....

Date of Birth:

.....

Edition January 2023

***For Carers and People with Learning Disabilities
to discuss choices in End of Life Care***

Contents

	Page
❖ Introduction	4
❖ Personal Choices	6 – 13
❖ Family Wishes	14-15
❖ Directory of Involvement	16-18
❖ Making Decisions	19
❖ Informed Consent	20
❖ Advance Care Planning	21-22
❖ NHS Continuing Health Care	23
❖ Care Checklist	24
• Physical	25-29
• Social	30-31
• Psychological	32-33
• Cultural Awareness	34 - 36
• Spiritual	37
❖ Physical and Psychological Changes at End of Life	38 - 40
❖ Responsibilities at the Time of Death	41
❖ Responsibilities after Death	42-43
❖ Bereavement Support	44-45
❖ Resource Information	46

❖ Care in the last days of life	48
❖ Discharge from Hospital Check List	See Appendix 1
❖ Responsibilities after Death Checklist	50-51
❖ Principles of 'Good Death'	52
❖ References	53
❖ DISDAT	See Appendix 1
❖ DNA/CPR	55-56
❖ Acknowledgements	57

Appendix 1:

1. Discharge from Hospital Checklist page 49-50
2. Disdat page 55

Introduction

End of Life care:

It can be very upsetting and shocking to be told that your loved one's illness cannot be cured, and you both may need help and support to cope with this.

End of life care is support for people who are approaching death. It helps them to live as well as possible until they die, and to die with dignity.

- National Health Service 2013

It enables the supportive and palliative care needs of both patients and family to be identified and met through the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

- National Council for Palliative Care 2011

This pack has been developed to be used by anyone who is caring for someone with a learning disability who has a diagnosis of a life limiting condition such as Dementia or Cancer.

Supporting someone at the end of their life can be very difficult for those involved. Using this pack will help to gather information about the wishes of both the individual and their family, which will help to ensure a person centred approach to care and reduce the difficulty of having to ask the family to make lots of decisions at the time of their loved one's death.

The pack also gives some specific care information with regards to the end-of-life as well as useful/practical information about what to do when a person dies.

Although traditional end of life care is defined as the last few weeks or days of life, this pack can be used from the point of diagnosis of a life limiting condition. This will enable the individual enough time to be as fully involved as possible. Early involvement is particularly important for individuals with Dementia who will sadly lose a lot of their skills and be unable to express their wishes as clearly as the condition progresses. Please see easy read version on the next page.

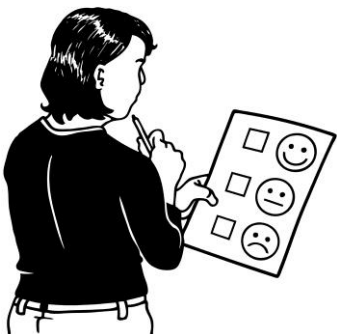
How this book will help you



It can be upsetting to be told that you are very poorly and won't get better. This is called a life limiting condition and it can be things like dementia and cancer.



This book will help you to be involved in your care and who will care for you.



It is important that people know what is important to you and the things you like and don't like.



This book will help you to plan what you would like to happen when you die.



You can ask your Key Worker, Carer, Family or Health Worker to help you to write in this book.

Personal Choices



My name is: _____

I like to be known as: _____



I live at: _____

Telephone Number  _____



My important person to be contacted in an emergency is: _____



They live at: _____

Telephone Number  _____

This may need to be filled in by a family member, Key Worker or someone who knows the person well.

Personal Choices



These ideas are what I would like _____



I have made a Will (this is what tells people who I am leaving my things to) _____

Yes No (Circle choice)

My Will is kept with _____

Address: _____

Tel:  _____

I have registered as an Organ Donor: (in case I want to give parts of my body to others after I have died)

Yes No (Circle choice)

Personal Choices



This was a Best Interest Decision:

Yes No (Circle choice)



People involved in bringing this plan together were:

Key Worker involved is:

Tel:





Personal Choices



Who else is important to me:



What matters to me about God or Friends or helping me to feel like I am loved?
See Appendix 1



Would I like to be cared for at home if I become very ill?



Yes No (Circle choice)

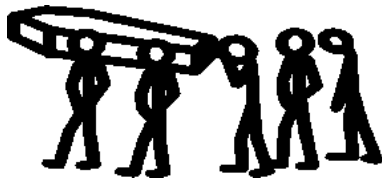
If not, I would like to go to:

(See resource information for Advance Care Planning)

Personal Choices



When I die



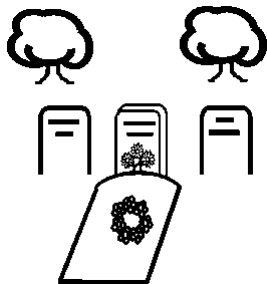
I would like to be buried

Yes No (Circle choice)



I would like to be cremated

Yes No (Circle choice)



I would like to be buried at: _____

I would like my ashes scattered at: _____

My special place is: _____



Personal Choices



My favourite flowers are: _____

I would like these flowers at my funeral:

Yes No (Circle choice)



My favourite song, or type of music is: _____

I would like this music at my funeral:

Yes No (Circle choice)

Reading



My favourite piece of reading is: _____

I would like this to be read at my funeral:

Yes No (Circle choice)

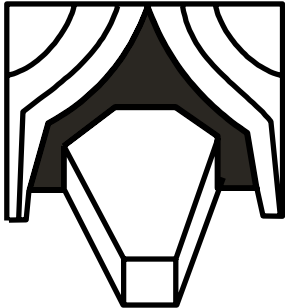
Personal Choices



Are there any things which you don't want at your funeral? _____



Do you have any items that are really important to you? _____



Would you like to have any of these items in your coffin with you?

Yes No (Circle choice)

Things I would like in my coffin with me are: _____

Personal Choices



Would you like someone to have these important items?

Yes No (Circle choice)

I would like my important things to go to: _____



Is there anything else which is important for your carers to know?

Personal Choices can be made into a formal decision by calling them Advance Care Plans (see page 44). Don't forget to use the Person Centre Plan/Communication Passport if the individual has them.

This is **not a legally binding document**. If decisions to refuse or accept treatment are needed, see flow chart on page 45.

Family wishes

Next-of-kin	
Address & Telephone number	
Any other family members who should be contacted	
Religion/faith/spiritual needs	
Do you know if your loved one has specific wishes about personal belongings?	
Any specific requests with regards to death rites	
Where would you like your loved one to be cared for in their last days of life?	
Preferred undertaker	
Who would you like to help you to make funeral arrangements?	
Cremation or burial	

Place of internment? Family plot, cemetery, scattering ashes?	
How will the funeral be paid for?	
What sort of plans should be made after the funeral (wake)?	
Who should be involved in the funeral and wake?	
Any other details which need to be recorded? E.g. – Will, advance directives?	

Directory of Involvement

	Name	Contact Details	How I will help
GP			
Psychiatrist			
Community LD Nurse			
Occupational Therapist (OT)			
Physiotherapist			
Speech & Language Therapist (SALT/SLT)			
Psychologist			
District Nurse (DN)			
Macmillan Nurse or LOROS Nurse			

Other			
Hospice at home (H@H)			
Social Worker (S/W)			
Advocate			
Carers Association			
Bereavement Service			
Clergy			
Funeral Director			
Pharmacist			
Dietician			
Nottingham Rehabilitation Service			

Continuing Health Care			
Rapid Intervention Team			
Other			

Useful numbers

University Hospitals of Leicester	0300 030 1573
Out of hours GP.....	0845 045 0411
Hospice at Home (9am-5pm Mon-Fri)	01509 410395
Hospice at Home (5pm – 9am)	0300 3007777
LOROS Hospice	0116 2313771
NHS	111

Resource Information

Making Decisions

When it comes to making decisions with an individual who is unable to clearly demonstrate their wishes the Mental Capacity Act 2005 gives very clear guidelines about how this should be done.

The 5 Statutory Principles:

- A person must be assumed to have capacity unless it is established that they lack capacity.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him/her have been taken without success.
- A person is not to be treated as unable to make a decision merely because it is seen as an unwise decision.
- Anything done for, or on behalf of, the person who lacks capacity must be done in 'their best interests'.
- Anything done for, or on behalf of, the person who lacks capacity must be 'least restrictive' of their rights and freedoms.

In order to decide if an individual has capacity to make a particular decision, a two-stage test must be applied:

Stage One – Does the person have an impairment of, or a disturbance in, the functioning of their mind or brain? E.g. – dementia, significant learning disability, physical or medical condition which causes confusion, drowsiness or loss of consciousness.

Stage Two - Is the person able to **understand** the information relevant to making the decision (you must demonstrate that you have provided support to help the person to understand the information in an appropriate manner.) Is the person able to **retain** the information or **use** that information as part of the process of making the decision? Is the person able to **communicate** his/her decision (whether by talking, using sign language or any other means?)

Resource Information

Informed Consent

All medical care requires the consent of the patient (or someone who is authorised to consent for the patient) before the care plan is carried out. Consent to treatments or procedures can be indicated verbally, in writing or by, for example, allowing procedures (such as blood tests), to take place, or by taking prescribed medication. In order to be able to consent to a treatment or procedure the health care professional must give the patient, or their authorised representative, information on the risks, benefits and potential effects of the treatment or procedure on future health and life. The information should be given using language or communication techniques which the person making the decision can understand.

The process of informed consent includes the following:

- Information is given in some way about the possible risks and benefits of the treatment.
- Information is given of the risks and benefits of other options, including not getting treatment.
- The opportunity to ask questions and get them answered to your satisfaction.
- Time is given if needed to discuss the plan with family or advisors.
- The information is used to help the patient make a decision which they feel is in their own best interest.

Every effort must be made by doctors and nurses to ensure the patient understands the purpose, benefits, risks, and other options surrounding the test or treatment.

Resource Information

Advance Care Planning

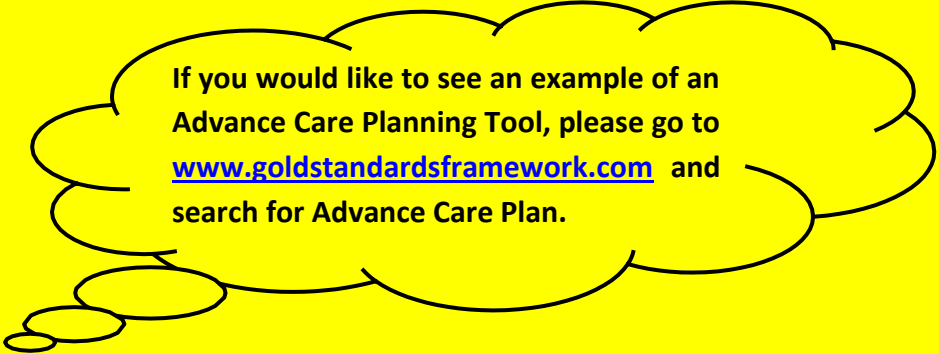
Advance Care Planning is an important part of the role of health and social care providers. This involves facilitating discussions with individuals and their carers about their preferences in regard to the type of care they would wish to receive as their condition deteriorates. The Advance Care Plan can then be used if the patient loses the capacity to make their own decisions. This enables health and social care workers to provide care and support in the way individuals would want.

Advance Care Plans can be used to express views on medical matters such as resuscitation, treatments, hospital admissions and preferred place of care. They can also be used to express wishes such as how a person wants to be dressed or the things which are important for them to have around.

An Advance Care Plan can be made verbally or documented in writing and is usually discussed when a life limiting illness has been diagnosed or as end-of-life approaches.

An Advance Care Plan cannot be made on someone else's behalf. If a person is unable to make an Advance Care Plan, then a 'best interests decision' on future care may be made based on information previously known about the individual and developed into a care plan.

Reference from Advance Care Planning: A Guide for Health and Social Care Staff,
www.endoflifecareforadults.nhs.uk



If you would like to see an example of an Advance Care Planning Tool, please go to www.goldstandardsframework.com and search for Advance Care Plan.

Discussing Advance Care Plans with individuals

Allowing someone to express their wishes about future plans is an important piece of communication. Advance care planning is a discussion between an individual and their care worker. The purpose of a plan is to allow an individual to express their wishes so that those wishes can be taken into account in the future when the individual can no longer make decisions.

Are you the right person to do this?

No

If you're not sure or do not understand the individual's clinical condition/treatment possibilities, do not continue with the plan. Ask a healthcare professional to lead the discussion.

Yes

Does the individual have a brain injury or impairment of the mind?

Yes

Assess the individual's capacity using the tests outline in the Mental Capacity Act. If the individual does not have capacity for making plans for the future, then best interest decisions will need to be discussed. If the individual has capacity for making future plans, continue the discussion.

No

Is this the first discussion of the individual's future plan?

No

Ask the individual if they wish to change any previous priorities of care. Ask permission from the individual to see any documentation of previous priorities of care if this is available.

Yes

Does the individual want to discuss their future care?

No

Review the individual's situation regularly. Check again when the individual's circumstances change and the individual wants to discuss future care.

Yes

Is the individual prepared to discuss end of life care?

No

Many individuals with early or slowly progressing disease, and some with advanced disease, will not wish to discuss care at end of life. Despite this they should still be offered the opportunity to discuss other aspects of future care. Ensure that discussion does not include questions or statements regarding care at end of life.

Yes

Does the individual refuse any treatment?

Yes

Do not use Advanced Care Plan to record this decision. Discuss with the individual the option of doing an Advance Decision to Refuse Treatment (ADRT) according to the Mental Capacity Act.

No

Ask open questions, for example (from Preferred Priorities of Care, 2007)

Q. In relation to your health, what has been happening to you?

Q. What are your preferences and priorities for your future care?

Q. Where would you like to be cared for in the future?

Allow the individual to control the flow of all information – i.e. if they do not want to talk about a certain aspect, ask those questions another time. Check if there are any other issues, e.g. 'Are there any other issues which are important to you?'

Does the individual refuse any future treatment?

Yes

Write down the key points of discussion. Offer the individual a copy if they want this. Ask the individual if and to whom they want copies given to e.g., key worker.

No

Document only that a discussion took place. Review the individual's future priorities – when the individual requests this OR when circumstances change.

NHS Continuing Healthcare

What is NHS continuing healthcare?

NHS continuing healthcare is the name given to a package of care which is arranged and funded solely by the NHS for individuals outside of hospital who have ongoing healthcare needs. You can receive continuing healthcare in any setting, including your own home or a care home. NHS continuing healthcare is free, unlike help from Social Services for which a financial charge may be made depending on your income and savings.

Who is eligible for NHS continuing healthcare?

Anyone assessed as having a certain level of care needs may receive NHS continuing healthcare. It is not dependent on a particular disease, diagnosis or condition, or on who provides the care or where that care is provided. If your overall care needs show that your primary need is a health need, you should be eligible for NHS continuing healthcare. Once eligible for NHS continuing healthcare, your care will be funded by the NHS but this is subject to review, and should your care needs change the funding arrangements may also change.

Whether someone has a 'primary health need' is assessed by looking at all of their care needs and relating them to four key indicators:

- Nature.
- Complexity.
- Intensity.
- Unpredictability.

How are the decisions made about who is eligible for NHS continuing healthcare?

The whole of the decision making process should be 'person centred'. This means putting the individual and their views about their needs and the care and support required at the centre of the process. It also means making sure that the individual plays a full role in the assessment and decision making process and gets support to do this where needed. This could be by the individual asking a friend or relative to help them explain their views, or advocacy support services may also be able to assist.

Contact Details - A continuing healthcare team is now based at St John's House.
Public: 0116 2951400

Further information: <https://www.gov.uk/government/publications/nhs-continuing-healthcare-and-nhs-funded-nursing-care-public-information-leaflet>

Care Checklist Physical

Symptoms	Tips to Help
<p>Pain</p> <p>Depending on the condition which the individual has, there may be a certain amount of associated pain, especially with cancer. Someone who has a learning disability or who is extremely ill may not be able to express their level of pain. It is therefore very important that all carers look for non-verbal signs of pain. You can use tools such as the DisDat Tool to assess when people cannot tell you about it. See Resource section for tool.</p>	<p><i>Sometimes repositioning the individual can relieve discomfort but if you are concerned that the individual is suffering from pain then it is important that this is discussed with the GP or Palliative Care Team as soon as possible. There are a variety of effective analgesic medications which can be given in a variety of ways. You should also consider other things that might cause pain, such as a not being able to pass urine, which can be treated quickly and reduce the need for strong pain medication.</i></p> <p><i>Common analgesic medications are Morphine and Fentanyl (opiates).</i></p>
<p>Nausea and Vomiting</p> <p>Nausea and vomiting sometimes occurs as the individual nears the end of life. The most common causes are medication, the disease itself and changes to the body's chemistry as organs stop working properly. People can experience nausea without vomiting and can vomit without feeling long periods of nausea.</p>	<p><i>To help people with nausea and vomiting we can make sure we keep strong smells to a minimum, for example strong cooking smells and perfume. Fizzy drinks and ginger preparations can reduce the feeling of nausea. Hypnotherapy and acupuncture may help. As nausea reduces a person's appetite, offer small, light meals but don't be distressed if they don't want to eat. Food supplements might be useful.</i></p> <p><i>There are many different types of medication for nausea and vomiting, (anti-emetics); the most common ones are Haloperidol, Metoclopramide, Levomepromazine, and Cyclizine.</i></p>

This section has highlighted the main physical symptoms the person may encounter towards their End-of-Life, providing tips on how to manage these symptoms. The individual's Health Action Plan will need to be reviewed to make sure their existing health conditions are not forgotten.

Physical

Symptoms	Tips to Help
<p>Restlessness and Agitation</p> <p>As the individual becomes more poorly they may seem disorientated and confused. This may develop into delirium or agitation. The individual may speak or shout out in a way which makes no sense, they may push anyone away or their arms and legs may flail out. Some people become frightened.</p>	<p>Good communication is really important and even when it is thought that the individual can no longer hear or understand it is still important to speak to them, explain all aspects of care and give reassurance. Be aware of how the individual communicates e.g. pictures, objects of reference. If comfort and reassurance is not effective then medication may be required.</p> <p>The most common medications used are Midazolam and Lorazepam.</p>
<p>Contenance</p> <p>The individual will need full support with meeting all their continence needs. Sometimes the individual may retain urine which will result in a distended (swollen), bladder and discomfort. With respect to the bowels there could be either constipation or diarrhoea, both of which could lead to discomfort.</p>	<p>Ensure high levels of personal care to refresh soiled/wet pads as necessary and meet personal hygiene needs. If there are signs of urine retention then seek medical advice as it may be appropriate for a catheter to be inserted. If there are signs of either constipation or diarrhoea then you should also get advice. Pain medication is likely to cause constipation so laxatives will be needed, for example Laxido.</p>
<p>Weakness/Drowsiness</p> <p>As the individual nears the end of life they will become increasingly weak and fall in and out of sleep. This is a natural part of the process as the body begins to shut down.</p>	<p>It is important to maintain all aspects of care but as the individual will tire easily it may be beneficial to breakdown tasks into smaller sections and allow the person to rest in between.</p>
<p>Risk of skin breakdown</p> <p>As the individual becomes less mobile their skin is at greater risk of developing pressure sores. The individual's skin may look and feel differently as they near the end of life. Skin can be clammy and look pale or blotchy. Facial features may appear gaunt and feet/hands may feel very cold.</p>	<p>High standards of personal care will help to maintain the integrity of the skin. Being clean, dry and warm will help to minimise the risk of developing pressure sores and regular repositioning of an individual when they become immobile will also help. The District Nurse can give advice on appropriate pressure relieving cushions and mattresses.</p>

Physical

Symptoms	Tips to Help
<p>Decreased Oral Intake</p> <p>It is quite normal for someone to stop eating and drinking as they are nearing the end; they no longer want or need it. However, it is important to realise that nausea and vomiting could be the cause of reduced oral intake. There may also be problems taking medication.</p>	<p>As the appetite decreases try tasty snacks, little and often, or favourite foods. Do not try to feed a person who does not want to eat or is having difficulty swallowing. Giving individuals food or fluid artificially is unlikely to be of benefit, and may cause discomfort. It will most likely be discontinued as a person approaches the end of life.</p>
<p>Dry/ Sore Mouth</p> <p>The reduced intake of food or fluids may result in the individual having an extremely dry mouth. Individuals often develop a general soreness in their mouth as well. Infections such as oral thrush may also develop.</p>	<p>Even though the individual may not want to drink, it is important to moisten and freshen the mouth. This can be done with sponges or gauze swabs, crushed ice or sips of fluid. Consider using lip balm on dry lips. Teeth should be cleaned regularly using a soft brush. Ask the care team or GP about mouthwashes and gels that can be used. Sucking pineapple chunks or kiwi fruit can help clean and freshen the mouth.</p>
<p>Risk of Falls</p> <p>As individuals become weaker they may become prone to falls. This can be due to the disease itself, medication or weakness due to poor dietary intake.</p>	<p>An assessment can be requested from your District Nursing team who can provide equipment to help minimise the risk of the individual falling. Referrals may be made to the GP for a review of medication or physiotherapists/occupational therapists for specialist advice on reducing the risks of falls.</p>

It is vital to take account of how the individual feels about their symptoms and how they want them managed.

Physical

Medication at End of Life

When it is recognised that an individual is in the last few days or hours of life it is usual for the doctor to review any medication that the patient is prescribed and to discontinue any that are no longer going to be of benefit. These include medications such as vitamins, statins (for cholesterol), blood pressure tablets, anti-biotics and iron. All medications that will provide comfort and relief of symptoms will be continued.

The doctor may prescribe medication for symptoms that the individual is not experiencing now but might experience as their condition progresses. This is called pre-emptive prescribing and means that if uncomfortable symptoms develop the nursing team can treat the individual straight away, avoiding any delays by having to wait for a doctor to call.

Syringe Drivers

When a person is no longer able to swallow medication because of nausea, weakness or unconsciousness the doctor and care team may prescribe medication to be given through a syringe driver. This is a small, portable pump that will give a person continuous medication over a twenty-four hour period. The team may also insert a small needle with a short tube just under the skin to administer medication; this is called a 'Butterfly'. The Butterfly and the syringe driver may be used alone or together and are very effective ways of keeping symptoms controlled without the individual having to have a lot of injections.

Complementary Therapy

Complementary Therapy can be used in conjunction with medical treatments to help with symptoms such as pain, anxiety, nausea and breathlessness. Popular Complementary Therapies include Aromatherapy, Massage, Acupuncture, Head Massage, Reflexology and Hypnotherapy. These treatments are not generally available from the NHS but can be provided by organisations such as LOROS and Coping with Cancer.

Be aware that cultural and religious issues may impact on symptom management.

Physical

Resuscitation Decisions

When someone has a diagnosis of a life limiting condition and they are in the final stages of the illness, it is unlikely that resuscitation would be successful. If it were successful then is it likely that the person would die soon after. It is felt that the trauma caused for both the individual and those involved in trying to resuscitate is far greater than the likelihood of success.

In hospital the doctor responsible for the patient may make the decision that resuscitation is not recommended, usually after speaking to relatives and the individual. A 'DNA-CPR' (Do Not Attempt Cardio-Pulmonary Resuscitation) form will then be completed. This still applies if someone then goes home or to a care home.

If the individual is at home or is in the community when they reach the end stage of life then it is the responsibility of the GP or suitably trained nurse to make the decision about resuscitation.

The clinician is then advised to discuss this decision and issues arising from resuscitation, with your loved one and yourself, unless discussing it would cause mental or physical harm. Once the form is completed, the original will be given to the individual and relevant people will be informed of the decision.

A DNA-CPR form solely applies to cardiopulmonary resuscitation, meaning that when your loved one's heart stops or they stop breathing, there will be no invasive procedure to restart the heart or breathing. Any other treatments that your loved one may require will be discussed as they arise.

The original signed and dated DNA-CPR form should be kept with the individual when moving through their journey. The DNA-CPR form applies across the entire East Midlands healthcare community, in all settings, including whilst in ambulance transfers.

East Midlands Strategic Health Authority (2011)

Leicestershire Partnership NHS Trust Resuscitation Policy (2012)

Physical

Out of Hours

Planning is essential in trying to avoid a crisis occurring 'out of hours' when the professionals who have been involved with the individual are not available.

If a person becomes suddenly ill at night or at weekends, then the on-call doctor may not be aware of the plans which have been made with regards to the 'preferred place of care'. It may result in an emergency admission into hospital which is often not what the person or their family want.

By careful planning and early involvement of appropriate palliative care teams, care needs can be better predicted. Provisions can then be made to meet these needs, regardless of when they change.

Discharge from Hospital

Before being discharged from hospital, especially if a person has palliative care needs, there are several questions to be considered before the individual comes home.

(See checklist in Resource Information Page 46)

Pharmacy

It may sometimes be difficult to obtain prescribed medication specific to palliative care. Make a note of the opening hours of your local pharmacy, your nearest out of hours service and whether your local pharmacy can order non-stock items quickly.

Social

Relatives / Family

It is important for the individual and their family to spend time together towards the end. If possible there should be flexible visiting arrangements and the opportunity to have private time together in a suitable environment.

Friends

Friends should also be allowed to visit. In a care home setting, even though an individual may be bed-ridden towards the end, their friends who they have lived with should be supported to visit at appropriate times, to sit with them. This will both support the individual who is dying and the friends when it comes to coping with bereavement. It may be appropriate to leave the bedroom door open at times so that the individual feels less isolated and involved in the general surroundings of the home if possible.

Communication

It is vitally important that good communication is maintained with all involved, at all times, to ensure that the wishes of both the individual and their loved ones are met. It may be appropriate to use communication aids, such as objects of reference to assist in achieving effective communication. Speech and Language Therapists can help with this. Good communication is also important to ensure high standards of care.

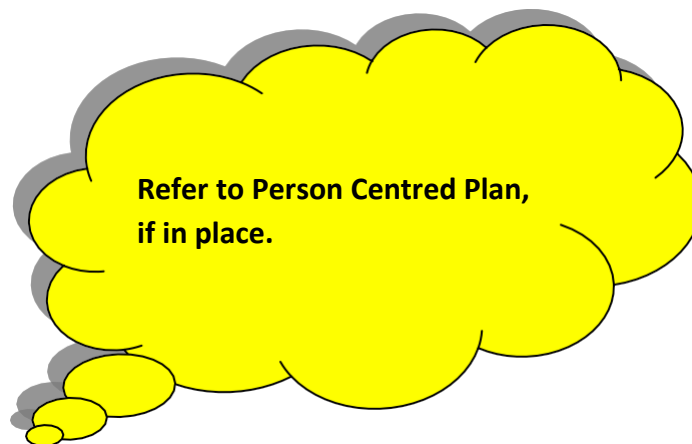
Financial

Consideration should be given to the financial status of the individual. If there is likely to be a financial problem in paying for funeral expenses or a significant sum of money left, then it would be good practice to discuss this with relatives to prevent them having to make difficult decisions at the time of death. It may be useful to set up a separate account or set aside some money each month once the diagnosis of a life limiting condition has been diagnosed.

Social

Personal belongings

You need to check if the individual has written a will. If they have not it may be appropriate to discuss this at an early stage as they may like to have a say on what happens to their belongings after their death. There may be some jewellery or special items which they would like to give to a friend or relative, for example. If this is the case then it is important to record this and discuss with relatives even if an actual will is not made.



Psychological

Dignity & Privacy

Right until the end, carers should remember that even though an individual may not be very responsive or able to do much for themselves, they are still a human being with feelings. Staff should care for them as if they are still able to be fully involved in making choices, and hear and understand everything which is being said. Carers should use speech throughout all aspects of care to explain to the individual what they are about to do to fully involve them. Carers should also maintain privacy by ensuring the individual is suitably covered and the door is shut for personal care. Carers should also be mindful that care settings can often be very noisy or busy and the dying person should be protected from this.

Personal Care

When it comes to personal care, the fine details should be remembered. Someone who was very proud of their personal presentation - for example always had neat hair - should be supported to look their best. Ensuring that their hair is brushed, nails are tidy and skin is moisturised could help to make a person feel a little better. We should always make an effort.

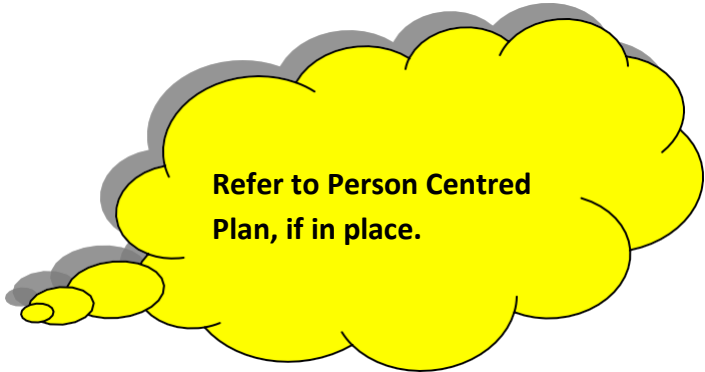
Psychological

Talking about death

It is not easy to talk about issues relating to death but it is important to be honest, and difficult subjects should not be avoided. The individual has a right to know about their condition and that they are dying. All efforts should be made to enable them to understand this if they want to. It is also important that appropriate relatives are also informed. This helps everybody with making the necessary plans and to work towards making it a 'good death' for the individual. It enables relatives to 'put their house in order' to deal with any issues that they wish to whilst they are still able. It is also really important to 'listen' to both the verbal and non-verbal cues which may indicate the patient's wishes.

Safety & Security

At times when the individual feels helpless and scared it is important that they are not alone and feel comforted and loved. Carers should ensure that as well as meeting all of their health and personal care needs that there is time to just be with the individual, to read a story, sing songs, play music or hold a hand to give reassurance. The use of complementary therapies may help the individual to feel less anxious and in a calmer state of mind. When many skills are lost, the senses are still responsive. Massage, aromatherapy or similar interventions can therefore be quite effective.



**Refer to Person Centred
Plan, if in place.**

Cultural Awareness

CHRISTIANITY

Where Jesus Christ is God, with varying rituals. There are formal sacraments, including baptism, marriage, forgiveness, healing etc. There is a holy book; the Bible, which includes the Old and New Testaments. Meeting rooms are all places of worship, and include Church buildings or Chapels.

After death – there are no specific prohibitions; there is diversity when arranging the funeral. Cremation is becoming increasingly popular, due to the expense of burial plots. A funeral commends the deceased to God, and comforts the mourners. Traditionally there is no objection in principle to organ donation or to a post mortem for legal or educational purposes.

JUDAISM

Where Yaweh is God. There are many differing sects and schools within the faith. The sacred book is the Old Testament and Torah, the Synagogue is the place of worship. Jews consider this life important, but that the soul lives on. No-one should die alone. Prayers may be said with the dying person, sacred music and artefacts used.

After death – family may attend the body, but it should not be touched, if possible, by Gentiles. There are specific funeral directors available. Burial should be as soon as possible, but not on the Sabbath. Jews do not believe in cremation. There are varying attitudes towards organ donation and post mortem.

HINDUISM

Hindus celebrate many Gods; there are a large number of groups, sects, schools of thought. Hinduism has influenced many other religions, such as Buddhism and Sikhism. There is no church with a hierarchy of priests, temple (Mandir) attendance is not important. Hindus believe in personal Gods, teachers, gurus. Hindus also believe in the way of life, spiritual and physical purity. Purification rites are important, and lack of these can inhibit prayer. Strict Hindus are vegetarian, never eat beef as the cow is sacred, and many Hindus fast regularly – one day each week, even when ill. Hindus believe in the wheel of life, reincarnation and Karma.

After death – Cremation, by a pyre or in a crematorium, usually lit by the oldest son, although now also by daughters. Ashes are scattered on holy water, the River Ganges, or other significant place. Death at home is preferred, for some Hindus choose to be on the

floor to die as then they are nearer to earth. Use of Holy Ganges water, and placing of Tulsi leaf in the mouth of the deceased. Use of statues, pictures, sacred music, prayed by family, friends and possibly priest.

There are auspicious dates on which to depart this life. 7th and 15th days of the lunar month being favoured.

Death from cancer can be seen as punishment for actions in this life, and a painful death may be anticipated. Mourning lasts for 12 days, when family and friends visit, and simple food is eaten.

SIKHISM

Sikhism is founded by Hindu mystic Nanak, from the Punjab. There is one God, who is Sak – truth. Since the death of the 10th guru in the 17th Century, the holy book, the Gura Granth Sahib is worshipped and recited daily and treated with great reverence. Priests are in Gudwara, a place of worship but no hierarchy. The main beliefs are reincarnation, karma and self-discipline.

Sikhs believe strongly in the 5K's and all Sikhs follow this; Uncut Hair, Iron Bangle, Wooden Comb, Cotton Underpants and Small Dagger.

After death – family may prepare the body, or the funeral company but the 5K's must remain. The deceased is to be cremated. Mourning lasts for 10-13 days, the anniversary of the death is marked. Sikhs have a great tradition of service to the community and to the nation.

ISLAM

Allah is God, is a religion and complete social system. There are two main sects – majority is Sunni, minority is Shi'a. There is no hierarchy of clergy; imams are trained and appointed by the mosque board or council. Mosques are autonomous, and relate to specific sects within the mainstream. Women rarely worship in Mosques, usually separated from the men. The Holy Book is the Qur'an, which is always treated with reverence. No sacred music or images are permitted.

Death from cancer can be seen as retribution and punishment, and diagnosis may not be disclosed, even within the family.

There are 5 pillars of Islam;

1. Declaration (Shahada) “there is no god but God, and Muhammad is God’s messenger” were the first words and last said by Muslims.
2. Prayer 5 times daily.
3. Zakhat – giving of alms, to charity.
4. Fast during Ramadan, unless a child, ill or menstruating.
5. Haji – pilgrimage to Mecca, if possible must be done at least once in a lifetime.

Death is seen as a way of life, and leading to blissful eternity.

After death – It is important that non-Muslims do not touch the body. All appliances and equipment should be removed. There are specific rituals of purification that take place at home or at the local Mosque. Muslim Burial council of Leicester can be contacted at local mosque, to help with funeral arrangement, particularly out of hours. Burial is essential within 24 hours after death. Mourning lasts for 3 days, and mourners are segregated when they visit the family of the deceased. In some instances women must remain indoors for 40 days following the death of husband, and see no other men than fathers, sons or brothers.

BUDDHISM

Is descended from Hinduism, there are two mainstreams Mahayana and Theravada Buddhism. Spiritual lead is the Dalai Lama – reincarnation of previous leader. There are no ministers, but tradition of monks and nuns, teaching by wise sages. The temple is the place of worship and home to the religious. Reincarnation is the core belief where actions in this life affect what the next life will be. Human effort matters, especially peaceful beliefs.

After death – Prayer, chanting and sacred music may be available to the dying person, who might want to stay alert. Religious artefacts and statues are used. Funerals are often celebrations.

Spirituality Religions/Cultural

Spirituality does not always need to be about religion; it can be about what makes the person feel good, positive or strong. It may be a favourite item, a good friend, having loved ones nearby, being treated with dignity and being involved and considered as an individual as much as possible for as long as possible.

Whether the individual, who is coming to the end of their life, is a religious person with a particular faith or not, they will have spiritual needs when they know death is imminent. It is often comforting for relatives to feel that their loved ones are going to be at peace.


Depending on the religion or faith of the individual, there may be different rituals and customs which need to be performed prior to and after death.

Some families may request that a member of their clergy visit their loved one, just prior to death, in order to pray and read 'last rites' with the individual. This is particularly true of the Christian faith. .

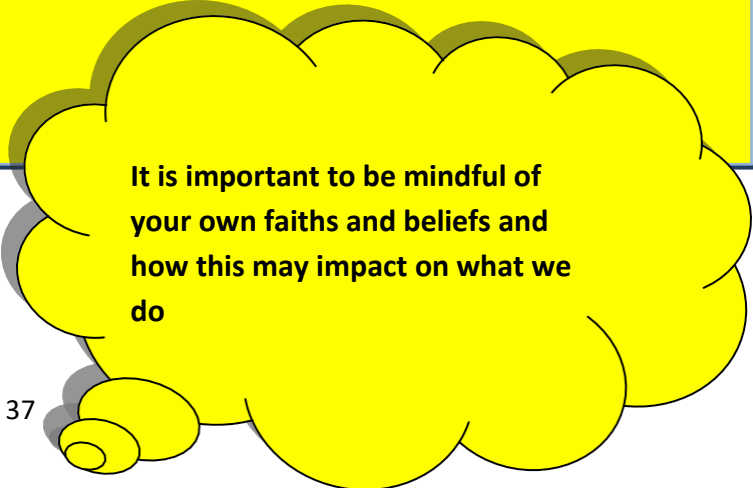
Different religions have various views about death and express this in a variety of customs and rituals. Muslims, for instance, prefer family members to wash the body of the deceased themselves and would be offended if the body were to be touched by a non-Muslim person.

Some faiths and cultures prefer cremation over burial and vice versa. Some have very clear times of when each custom or ritual should take place.

Activities after a funeral differ as well. The traditional Irish Wake for example, is a celebration of life, traditionally in the local pub which involves 'toasting' the deceased, singing and dancing. In grief, some beliefs are very clear on periods of official mourning depending on the status of the deceased. (See Resource Information for more specific details.)



Refer to Person Centred Plan, if in place.



It is important to be mindful of your own faiths and beliefs and how this may impact on what we do

Physical and Psychological Changes at the End of Life

As people approach the end of their life, various changes will take place both physically and psychologically. Knowing what to expect and what changes may take place will help to reduce your anxieties at this distressing time.

Consciousness

Changes in a person's consciousness at the end of life are normal and the term '*withdrawing from the world*' is often used. The individual's level of consciousness will slowly decrease, and they will spend more time asleep than awake. They may lose interest in their surroundings and may not recognise familiar people around them, sometimes talking to people that they have known in the past. It can help to talk to the patient about daily events and people who they know, even if they cannot respond to you. It is particularly important tell the person what you are doing for them when providing care such as administering medication, moving or carrying out personal hygiene.

Food and Drink

When a person is dying their need for food and drink reduces as the body no longer needs high levels of nutrients. The individual will probably not feel thirsty or hungry but if they do and are unable to swallow they can be given fluids through a small needle that is placed just under the skin. As the body slows down is it unable to use the fluid and it may collect around the lungs causing noisy breathing. At this point the fluids will probably be stopped. At this time any artificial feeds will also probably be discontinued. If the feed is not being used by the body the individual can experience discomfort and potentially an increase in nausea and vomiting.

Dry mouth is more likely to be caused by breathing through the mouth or medication; therefore it is vital that mouth care is carried out regularly to keep the mouth moist and clean.

Physical and Psychological Changes at the End of Life

Noisy Breathing and Breathing Difficulties

Noisy breathing can be caused by fluid collecting in the breathing passages due to artificial fluid or difficulties in swallowing or coughing. This can be very distressing to hear but is rarely a problem for the person themselves. Position and medication changes may help if the person is distressed by the symptom.

Breathlessness may occur is common at end of life and can be caused by anxiety. Medication can be used to help with anxiety and breathlessness and occasionally, oxygen helps. Towards the end of life the body's need for oxygen reduces and breathlessness ceases to be a problem. In the last hours breathing slows down and there may be pauses between breaths. This is normal.

Skin

Several changes may occur to the skin when an individual is dying. The skin's colour will change, becoming pale and there may be some blotchy, discoloured areas. You may also notice a grey colour around the mouth. The skin may feel moist and over time it will become cooler. Skin may also become more sensitive to touch and extra care will be needed when moving them.

Restlessness

Restlessness in a person who is dying is very distressing to see but it is a normal part of the natural dying process. The person may be agitated or try to climb out of bed. They may be shouting, jerking or twitching or they may experience hallucinations. This could be emotional distress or side effects of the medications they are receiving. It may also be occurring naturally due to chemical changes in the body. Physical symptoms such as pain, urine retention, constipation or nausea may also cause restlessness. Your GP and nursing team will investigate any such reversible cause for restlessness. Medication may be needed to help the individual to feel more settled, but talking with someone and being near them can help a lot.

Physical and Psychological Changes at the End of Life

The Final Moments of Life

For most people this time is very peaceful. Breathing becomes increasingly slow and irregular with long gaps in between breaths. Their abdominal (tummy) muscles control breathing instead of the chest muscles so that the tummy can be seen to rise and fall every time they breathe. Eventually breathing will stop altogether. For some people this can take a very short amount of time and for others it can last several hours.

Responsibilities at Time of Death

DNA-CPR means `Do Not Attempt Cardio-Pulmonary Resuscitation`.

(See page 24 for more information on DNA-CPR forms)

If the person **does not** have a '**DNA-CPR**', call an ambulance (999) and if able, start resuscitation.

If the person has a '**DNA-CPR**' in place, don't panic, **do not** call 999, **call the individual's doctor, or the 'out of hours' number – 0845 045 0411**

NB. If there is any reason to suspect that death was not due to natural causes, do not touch or remove anything from the room or person. Call the police straight away.

Responsibilities after Death

❖ **Verification of Death / Medical Certificate of Death**

If the doctor has not treated the patient during the last illness or seen the patient within 14 days before death, then the death must be reported to the coroner. This does not however mean that there will need to be a post mortem if medical records demonstrate that there was reasonable evidence that death occurred from natural causes.

❖ **Registration of Death**

The death must be registered with the registrar of 'Births, Deaths and Marriages' within 5 days (unless the coroner is involved, in which case they will give permission to do so when appropriate).

Death has to be registered by the next of kin / family when possible. The registrar will issue the 'Death Certificate' which is used as evidence to sort out personal circumstances following death, for example financial matters.

The registrar will also issue the 'Certificate for Burial or Cremation'. Funeral directors will need this to be able to proceed with making funeral arrangements.

❖ **Planning the Funeral**

Dependent upon the religious beliefs held by the individual and their family, there may be very specific rituals at the time of and following death. This may decide whether the individual is to be cremated or buried.

- ❖ **Cremation** – No one can be cremated until the cause of death is definitely identified. Five different forms are required for a cremation to take place – **Application Form** signed by next of kin / executor of estate, two **Cremation Certificates**, signed by two different doctors (however if the coroner has been involved they will provide a Certificate of Cremation so the other two are not needed.) **Certificate Form F** - signed by medical referee at crematorium. And the **Certificate for Burial or Cremation** - issued by registrar.

Responsibilities after Death

- ❖ **Ashes** – scattered on the garden of remembrance at the cemetery or a favourite spot, or they can be buried in churchyard or cemetery.
- ❖ **Burial** - Most churchyards in towns are now closed to burial due to lack of space. Cemeteries are owned by the local authority and fees vary according to whether a person has lived within the boundaries of the authority area. Some individuals may have a pre-bought single plot grave or the right to be laid to rest in a family plot.

(See Resource Information for checklist page)

Bereavement Support

Identify who is bereaved

When a person dies, especially if they have lived in a care home, it is important to identify all of the people who their loss affects. The family and relatives will mourn the loss of a loved one, but others will feel the loss too. These people may include those who have lived with the person who has died, as well as the staff who have cared for them on a day to day basis. It is important that all those affected are able to express their emotions and take practical steps to grieve accordingly.

Communication and Emotion

At the time of death it is always going to be difficult to inform others, especially family. It is always desirable to have warned relatives that death is expected. This gives them the opportunity for last visits, to say goodbye and it also reduces the impact of the death when it occurs. It is important to be honest and clear and to warn the person that you have bad news before informing them. You may need to repeat yourself if the individual finds it difficult to understand or accept what is being said to them.

Bereavement Support

Although it is important to be professional, it is acceptable to show emotion and to allow others to see that the death has been upsetting for everyone - and that it is all right to cry. It is positive to reflect on things people have done to make it a 'good death' for the individual who died. It is also good to encourage conversation about the deceased and to talk about happy memories involving them

Practical Steps of Remembrance

It is useful to take some practical steps towards acknowledging the loss of a loved one. This helps to confirm the idea that someone has gone. Supporting people to attend the funeral is a good way for people to say 'goodbye' when it is appropriate. Having a book of remembrance with photographs and memories is good to use as a prompt for individuals to remember people in a positive way. Having a 'wake' after the funeral or a 'celebration of life' gathering is a good opportunity to chat to others about the deceased and to celebrate in their honour all the good things which they gave to the group. Another practical step might be to choose a particular item belonging to the deceased to keep as a way of remembering them in a very personal way.

Concerns and Problems

After a death occurs it is positive to return to a 'normal' routine shortly afterwards to reinforce that life goes on and that it is all right to continue with every day activities without the deceased.

If there are concerns about anyone being able to grieve and come to terms with the death of another then it may be appropriate to seek the support of a counsellor or psychologist, the grieving process is very individual and can take many months or even years. There are no rules with bereavement and a wide range of emotions which can be displayed at the time of loss.

Resource Information

If it is established that the individual does lack capacity to make the decision then this should be done as a 'Best Interests' decision which must involve the views of all relevant people, both professionals and relatives and should be made with respect to the individual's own beliefs and preferences if known. Be careful to fully document all decisions made with a clear description of how they have been made and what has been done to involve the individual in the process.

Care in the Last Days of Life

'Care in the Last Days of Life' is an approach which helps Doctors and Nurses to focus on care in the last hours or days of life when a death is expected. It is tailored to the person's individual needs and includes consideration of their physical, social, spiritual and psychological needs.

'Care in the Last Days of Life': when Doctors and Nurses looking after your loved one believe that there has been a change in the individuals' condition that indicates that your loved one is dying. They will discuss this with you.

'Care in the Last Days of Life' is a document that outlines the best care at the end of life, irrespective of your loved one's diagnosis, or whether they are dying at home, in hospital, in a care home or hospice.

The Doctor or Nurses may ask you about what you understand about the current situation. You should be given an opportunity to ask any questions that you may have.

If you have any further questions you can ask your health care professional.

Discharge from Hospital Checklist

Planned Hospital Discharge for:.....Date:.....

Issue	Tick when completed	By who	Comments / Notes
Staffing – are extra staff needed to provide an appropriate level of support? Has extra staffing been arranged?			
Equipment – will specialist equipment be required? E.g. specialised bed, pressure mattress, wheelchair, hoist? Has equipment been made available?			
Transport – how will the individual be transported home? Is an escort required? Have arrangements been made?			
If a Do Not Resuscitate decision is in place, is a DNA-CPR form available to take home?			
Have arrangements been made for take home medications? Are they available on the ward?			
Prescription to GP – is the GP aware of discharge prescription?			
Check medication available from Pharmacist for repeat prescription?			

Discharge from Hospital Checklist

Planned Hospital Discharge for:.....Date:.....

Issue	Tick when completed	By who	Comments / Notes
Has GP been informed of discharge?			
Has Palliative Care Team been informed of discharge?			
Have family been informed of discharge?			
Has NHS Continuing Health Care been completed if appropriate?			
Speech and Language Therapy Assessment? (Where eating and drinking is difficult)			

Responsibilities after Death Checklist

Name of Deceased:.....Date of Death:.....

Description of Responsibility	Completed / checked by	Date	Comments/notes	Tick when completed
Medical Verification of Death				
Inform Next of Kin				
Lay-out Deceased, if appropriate				
Notify Undertaker, arrange for collection of Deceased				
Inform other Service Users who are present at time				
Inform other Family Members as requested				
Inform other Staff members, before they next come on duty				
Inform Members of Professional Team				
Registration of Death				
Inform Department of Work & Pensions – stop benefits				
Make funeral arrangements as necessary with agreement of family				
Make arrangements for 'celebration of life' / memorial opportunity for service users				

Responsibilities after Death Checklist

Name of Deceased:.....Date of Death:.....

Description of Responsibility	Completed / checked by	Date	Comments/notes	Tick when completed
Arrange de-brief session for Staff team				
Make necessary arrangements of financial matters – funeral payment, close bank accounts etc, as agreed with family				
Make necessary arrangements of personal belongings as agreed with family				

Principles of a 'Good Death'

- ❖ To know when death is coming and to understand what can be expected
- ❖ To be able to retain control of what happens
- ❖ To be afforded dignity and privacy
- ❖ To have control over pain relief and other symptom management
- ❖ To have choice and control over where death occurs (at home or elsewhere)
- ❖ To have access to information and expertise of whatever kind is necessary
- ❖ To have access to any spiritual or emotional support as required
- ❖ To have access to hospice care in any location, not only in hospital
- ❖ To have control over who is present and who shares the end
- ❖ To be able to issue advance directives, which ensures wishes are respected
- ❖ To have time to say goodbye and to have control over other aspects of timing
- ❖ To be able to leave when it is time to go, and not to have life prolonged pointlessly

(Age Concern 1999)

“You matter because you are you and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die”

Dame Cicely Saunders, Nurse Physician and writer, a founder of hospice movement (1918-2005)

References

- Age Concern – planning a funeral
- Alzheimer’s Society – grief & bereavement
- Alzheimer’s Society – Mental Capacity Act 2005
- Continuing Health Care
- Department of Work and Pensions – what to do after a death in England & Wales
- NHS & Marie Curie Cancer Care
- NHS East & Central Lancashire – best interests at End of Life
- NHS End of Life Care Programme – Advance Care Planning
- NHS End of Life Programme – the Gold Standards Framework
- Preferred Priorities for Care (Easy read)
- NHS North East - End of Life Care
- Symbols - from picture bank
- The National Council for Palliative Care – End of Life Care Strategy
- Disdat
- DNA CPR – www.emas.nhs.uk/contact/care-decisions
- Cultural Awareness – Sheila Markum – Broadening Horizons Project 2009
- The National End of Life Care Programme 2013

DisDat is intended to help identify distress cues in individuals who have severely limited communication.

It is designed to describe an individual's usual content cues, thus enabling distress cues to be identified more clearly.

NOT a scoring tool. It documents what many carers have done instinctively for many years thus providing a record against which subtle changes can be compared.

Only the first step. Once distress has been identified the usual clinical decisions have to be made by professionals.

Meant to help you and the individual in your care. It gives you more confidence in the observation skills you already have, which in turn will give you more confidence when meeting other carers.

www.disdat.co.uk



Section 1: DNACPR Category. Delete A or B to identify which applies

A. For a person at the end of life. DNACPR applies across all care settings. Review necessary. **OR**

B. DNACPR decision for periodic review during course of care or on discharge. State the first review date in section 5. (Should option A become applicable a new form must be completed)

ORIGINATED BY (Optional):

e.g. Doctor in training (PRINT) Signature
C. No Date

ORIGINATED BY AND/OR ENDORSED BY (Obligatory):

Responsible clinician/nurse (PRINT) Signature
Designation Date Organisation
If applicable GMG No

Addressograph Label

Patient name:

Address:

Date of birth:

NHS No:

Telephone No:

Location of patient when DNACPR form completed

Section 2: Reason for DNACPR

(Please tick those that apply):

1. Unlikely to be successful because... **D**
Patient condition indicates that CPR is

CPR is not in accord with a valid Advance Decision to Refuse Treatment

Patient does not consent to GPR

Section 3: Communication with patient and carer (relevant others)

(Tick all that apply):

It is good practice to explain why CPR will not be attempted, unless doing so would cause unnecessary distress.

This **has** been discussed with the patient

This **has** been discussed with (name) on

..... Re: Referral to patient
contact details

This is **has not been** discussed with the patient because it would cause unnecessary distress in their lack of capacity (delete as applicable)

This **has not** been discussed with any relevant other e.g. family/carer

be cause
Fully record details of all CPR discussions in the patient's notes

Section 4: Complete section below only for patients who lack capacity

Does the patient have a legally appointed and registered welfare attorney? **Yes No**
Have they been consulted and discussion documented? (if yes to question above) **Yes No**
If no attorney or others to contact in the patient's best interests, has an IMCA been contacted? **Yes No**
Confirm that decision made following the best interests process of Mental Capacity Act **Yes No**

Fully record details in the patient's notes

Section 5: DNACPR review. Please complete if indicated by B in section 1 on the date stated below

Date of review	Reviewer's name (capitals)	Reviewer's signature	Next review due	Designation & contact details	Location of patient

Section 6: IF DNACPR CANCELLED - CLEARLY CROSS THROUGH DOCUMENT WITH 2 LINES NAME, DATE AND SIGN with a reason for cancellation

Section 7: Organisational communication

The clinical team must ensure the DNACPR paperwork accompanies the patient on transfers and that professional colleagues receiving the patient are aware of the decision

Patient's GP Telephone No Professional contact of home Name
Address Telephone No Address

Has person in charge of patient's daily care (e.g. GP, Community Nurse or Care Home) been informed **Yes No**

A copy should be kept in the notes exclusively for audit purposes and marked as COPY.

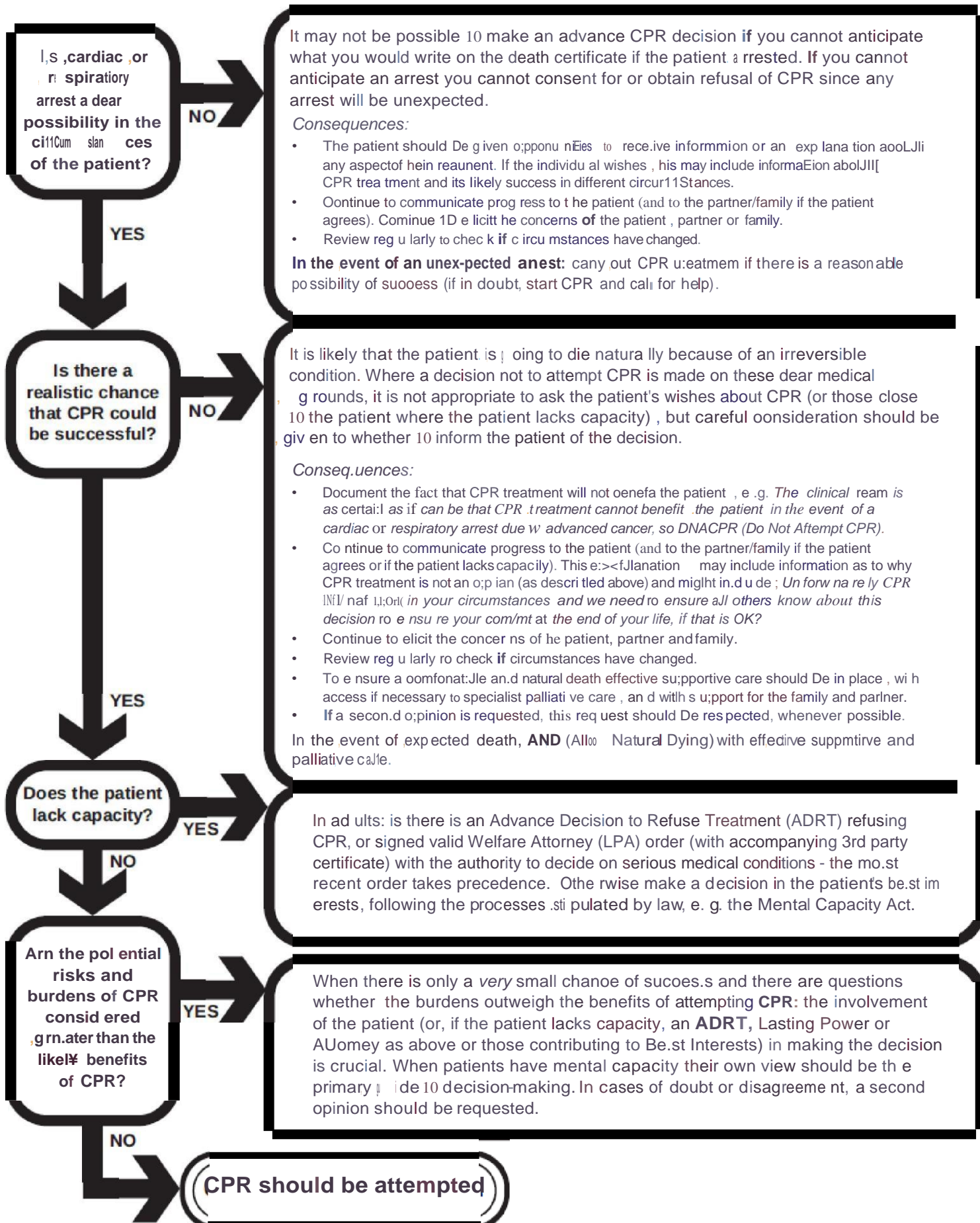
When at home or place of care/residence ensure the original form is accessible to visiting health or social care professionals. E.g. place the form at front of community notes or message in a bottle. Ensure it is ready should an emergency/urgent call be made

Does the patient have a preferred place of care at the end of life? **Yes No**

If yes, **w** Tick Box - Home Hospital Care Home Hospice Other (please state)

Healthcare Professionals Completing This DNACPR Form

Decisions will vary according to circumstances and local arrangements. In general this should be the most senior available professional immediately available. Whilst in the acute hospital or community setting, this will be a senior experienced doctor or nurse, who has undertaken appropriate training and is confident in making and making a decision, according to the requirements of their employer. This decision should be shared with the Multi-disciplinary Team at the next opportunity.



Acknowledgements

Many thanks to all those who contributed to the development of this End of Life package for adults with learning disabilities.

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(Palliative Care for People with Learning Disabilities Working Group)
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- ❖ End of Life Care Practice Trainers (Leicestershire County and Rutland Community Health Services)
- ❖ Skills for Care Limited (Marie Lovell)

This guide can be made available in other formats and languages if required.

Any comments welcome to
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