



Doing it my way

.....

**A COMPREHENSIVE GUIDE TO
END OF LIFE CARE FOR PEOPLE
WITH LEARNING DISABILITIES**





Facilitator guide

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About the authors

Developed by the Doing it My Way End of Life Care focus group: Catherine Wood, Judith Cooper, Marnie Walker, Sally Arrey, Nicky Lyall, Vivian Lamptey and Joanne Seed.

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What does this pack contain?

The DVD

The DVD contains a presenter-led film that will talk you through each stage of the training pack. The film is split into individual chapters, so you may choose to watch one section and then consult the relevant documents, or watch the full film right through before looking at the documents.

Doing it My Way tools and documents

Your 'Doing it My Way' package contains a variety of documents, tools and resources designed to help you deliver specially tailored care for people with learning disabilities.

1. (Yellow) Guidelines for Implementing Relevant Documentation in End of Life Care

This document is your guide to 'Doing it My Way' at every stage of a person's life. It explains which documents to consult and when, along with details of supplementary information you should gather using the various appendices.

2. (Blue) A Comprehensive Guide to End of Life Care for People With Learning Disabilities

This document takes you step-by-step through the various stages needed to implement 'Doing it My Way' in your service. It covers every stage from initial planning, to getting your team on board, to caring for someone in the final days of their life.

3. (Pink) Standards on End of Life Care For People With Learning Disabilities

This document is designed to help you understand the standards of care you should aim to provide when planning, implementing and reviewing care.

4. (Green) Probabilities of Life Expectancy - or POLE

This tool explains the various stages of a person's health, and the way in which their needs change. It contains details of specific assessment tools you can use to determine which stage of life someone is at, along with examples and case studies for each stage.

5. (Teal) Communication

This document will help you identify and develop the communication skills needed to talk about End of Life care with your client and their loved ones.

How to use this pack

Familiarise yourself with the contents, then play the DVD. You should only watch the DVD in conjunction with the rest of the training pack, as the documents expand on the messages covered in the DVD.

Ensure you provide attendees with time to absorb the information and ask any questions. Then you can follow the pack's expansion into end of life care for everyone in your care.

1



GUIDELINES FOR IMPLEMENTING RELEVANT DOCUMENTATION IN END OF LIFE CARE

The following flowchart is designed to provide help and guidance to care staff members when implementing specific documentation to monitor an individual's health. Naturally, it should be adapted to allow for personal circumstances wherever necessary.

PRIOR TO MOVING IN:

- Medical History – document to be completed once - *Appendix 1*.
- Mental Capacity Assessment form – to be completed annually, or when required – *Appendix 2*.
- Client Positive Risk Assessment 3
- Mental Health Risk Assessment 4



AS SOON AS POSSIBLE AFTER MOVING IN:

- Weight chart (to gain a baseline) - monthly, or more often in the event of rapid weight loss or gain – *Appendix 5*.
- Waterlow (to gain a baseline) - monthly, or more often if health starts to deteriorate - *Appendix 6*.
- Bowel chart – daily – *Appendix 7*.
- Daily records – daily – *Appendix 8*.
- Moving In document – to be completed once – *Appendix 9*.
- POLE leaflet distributed to families – to be given to families before completing the Advance Care Plan – *Appendix 10*.
- My Advance Care Plan – once reviewed, then annually during PCP meeting – *Appendix 11*.
- Services that an individual comes into contact with – document to be completed once and amended as and when necessary – *Appendix 12*.
- Person-Centred Planning Meeting – annually – *Appendix 13*.
- PCP Action Plan – annually – *Appendix 14*.
- National Early Warning Score (to gain a baseline) – Monthly or more often if needed - *Appendix 15*.



OPTIMUM HEALTH:

- Health Care Guidelines – reviewed monthly and changed if necessary – *Appendix 16*.
- Menstruation Chart (if applicable) – as and when necessary – *Appendix 17*.
- Health Care Diary – after appointments, discussions or telephone calls with other healthcare professionals – *Appendix 18*.
- PRN guidelines (if necessary) – reviewed monthly or more often if required – *Appendix 19*.

DEPENDENT UPON PERSONAL REQUIREMENTS:

- Fluid Balance chart – completed daily – *Appendix 25.*
- Health Action Plan - completed once and reviewed as and when required – *Appendix 26.*
- Nursing Care Intervention Plans – completed as and when required, if in receipt of nursing Care – *Appendix 27.*
- Assessment of nutritional status – *Appendix 28.*



CARING AT THE END OF LIFE:

- 'Just in case' or Anticipatory Medication – depends upon personal needs but could be as frequent as hourly. GP and District Nursing Team will provide guidance at this stage – *Appendix 24.*



PROGRESSION OF DISEASE WHICH NO LONGER RESPONDS TO TREATMENT:

- Hospital tracking form (if applicable) – if hospital admission takes place, to be filled in daily until the individual returns home – *Appendix 22*
- Weight chart (to ensure changing needs are met) – monthly or more often if necessary to monitor weight gain or loss.
- Waterlow chart (to ensure changing needs are met) – monthly or more often if necessary to monitor deterioration of tissue.
- DNA CPR – *Appendix 23.*



LIFE THREATENING CONDITIONS THAT RESPOND TO TREATMENT:

- PRN Guidelines (if applicable) – reviewed monthly or more frequently if necessary.
- National Early Warning Score (to monitor observations and enable fast response) – monthly or more often if necessary.



CONGENITAL ABNORMALITIES THAT WILL AFFECT LIFE EXPECTANCY:

- Record of seizure chart (if applicable) – filled in after seizure - *Appendix 20.*
- Complete OK Health Check – annually in PCP meeting – *Appendix 21.*
Note: There may be a fee to use this health check and you may wish to design your own.

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**A COMPREHENSIVE GUIDE TO
END OF LIFE CARE FOR PEOPLE
WITH LEARNING DISABILITIES**

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*Developed by the 'Doing it my way' End of Life care focus group:
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Introduction



Providing first class support towards the end of someone's life is a vital part of caring. And it doesn't matter if you currently have no plans in place for end of life care. This comprehensive guide has been especially developed to lead you through every stage in the caring process.

Although many of the people you care for will be currently healthy and well, it is important to have such plans in place in the event that their health takes an unexpected turn and their needs change.

By simply following the step-by-step recommendations described here you can be sure to provide the best possible care for the people you support as they approach the end of their life.

This comprehensive guide is part of an End of Life pack which also includes the Probabilities of Life Expectancy tool as well as outlining the standards we aim to meet.

What, Why, How, When and Where?

What End of Life care is all about

It's an important part of your role to ensure that every person receives the highest standard of care. And this doesn't mean just in the person's life time, but also in the period leading up to their death and the difficult few days thereafter.

Providing a person with comforting End of Life care, and ensuring that their needs and wishes are met once they have died, is all part of the caring process. This may include communicating funeral wishes, or helping to make advance decisions or writing a will. This can be done in a sensitive way that is not distressing to the individual and their family. This will then provide them with the comfort and knowledge that you and your team are well prepared for when the time comes to put these plans into action.

Why it's so important

Nowadays, people are living longer than ever before. And although more than half a million people in Britain now live in care homes, more and more people are choosing to die in their usual place of residence, which for many, is at home. This means there's every chance that one of the people you support may come to the end of their life whilst in your care.

- Therefore, it is vital to prepare both yourself and your staff for such an eventuality. And that means having all the relevant plans in place to ensure the people you support have 'a good death'. This will increase confidence and also help you learn from experience and improve the care you give to people.

How to improve your level of care

This document provides a step-by-step guide on how to put into place an End of Life plan, as well as how to make them effective and useful in your everyday practice. You can seek advice from lots of different healthcare professionals when planning End of Life care and this is also discussed throughout this support plan.



When you should start to plan

By consulting this support plan, it's clear that you're already thinking about planning End of Life care in your care home. For an individual, a good time to start thinking about their end of life care is the moment when you accept them as a new referral or very soon afterwards. This will not only prepare you and your staff team, but also help to lay foundations with family members who will naturally be heavily involved in the process. It will also reassure them that everything possible is being done to meet the wishes of their loved one.

Where you should start the process

Discussing End of Life care with family or significant others can often be uncomfortable. To minimise this, the meeting should take place at the home the person lives in, and everybody involved in caring for the person should be invited. This includes the End of Life coordinator and any other relevant healthcare professionals, plus the individual themselves and their next of kin or family. If no close relations are available then an advocate should be invited to attend.

By making everyone feel more comfortable, it will be a little easier to talk about End of Life care. Our leaflet *'Supporting your relative throughout the whole of their life'* is a good way to introduce the subject to family members. (Your service should have copies of this document).

Stage 1

**Getting your
staff team
on board with
End of Life care**



In order to successfully put into place End of Life care plans, you'll need the full support of every member of your team. So it's vital that everyone is involved at the outset, including any other healthcare professionals, such as a social worker or GP, who have cared for the individual.

A good place to discuss End of Life care is in staff meetings where you can often gain valuable ideas from your team. Of course, some staff may be reluctant to discuss such a sensitive topic. However, good leadership skills, knowledge of the subject and a willingness to share this information with colleagues, should all help to overcome any negativity and motivate staff members to take an active interest.

Involve all relevant healthcare professionals

It's a good idea to gather in advance the details of people who may provide care to the individual once they are approaching the end of their life. Making yourself known to local community palliative care teams before your client needs their services is a good way to establish and build relationships. The sooner you make contact, the sooner they can help you with any queries or concerns you may have.

Appointing a member of staff to take the lead in End of Life care is a good idea. This could be either the home manager or deputy manager, or someone who has an interest in the field. If a couple of members of staff want to perform this role, then working together will provide support and motivation as well as reduce the workload. This includes reviewing End of Life care plans, working with other healthcare professionals to ensure good care at all times, communicating with family members, keeping colleagues up to date, and taking part in End of Life care training sessions with the rest of the staff team.

Stage 2

Proactive planning



Documentation

It is important to keep records of everything relating to the End of Life care for each person. This can be incorporated into their existing files, or a new file can be set up that focuses completely on their End of Life care. This second method is recommended with an index at the front, as it is much easier and quicker to find the relevant information.

Take a look at the *'My Advance Care Plan'* document in your End of Life information pack. Developed with the individual in mind, it's an easy-to-read guide that outlines all of a person's wishes with regard to what happens when they die. It prompts thoughts such as: *'What would I like to do with my belongings when I die?'* and *'Would I prefer to be buried or cremated?'*



Plan ahead and keep all files up to date

This document should be kept in the person's file and regularly reviewed and updated. It's called an **advance statement**, and it helps to make up an **advance care plan**. This is the name of the process of discussing and planning ahead, in preparation for the worsening of an individual's condition. It takes a person's wishes and thoughts into account, and should be followed when their health deteriorates. The other part of an advance statement is an Advance Decision to Refuse Treatment (ADRT), which is discussed below.

Advance Decision to Refuse Treatment (ADRT)

An Advance Decision to Refuse Treatment sets out very clearly what a person does not want to happen in the end stages of their life. For instance, they may choose not to have treatment if their condition worsens. An ADRT can only be made when a person has the mental capacity to decide which potentially life-prolonging treatments they would like to decline. It is written to be used when they can no longer communicate or have the mental capacity to make informed decisions. It must be witnessed and dated to become a legal document.

Do Not Attempt Cardio Pulmonary Resuscitation

DNACPR stands for Do Not Attempt Cardio Pulmonary Resuscitation.

It is a decision made in advance by medical professionals, such as a GP or clinical nurse specialist, to prevent the attempt of CPR when a person's heart stops.

The general public believes that someone who receives CPR has a 50% chance of being resuscitated. In truth, this figure is closer to 10% and could even be lower if the person has underlying health problems.

When a person's heart stops of a natural process, CPR *does not work*. It should be remembered that cardiac massage is designed only to maintain blood flow prior to advanced treatment such as defibrillation, medication and hospitalisation.

It is important to explain to family members or next of kin that in any other circumstances, such as choking, the person will still receive treatment. It is only when the person dies that no attempt will be made to restart the heart or lungs. The person themselves should also be told of this decision unless it is thought that it would cause them psychological harm and this must be clearly documented in line with new laws.

It should be noted that a person or their family cannot insist that CPR is performed. This remains a clinical decision since it is unethical to offer a futile treatment. However, such cases should be handled sensitively with evidence being presented that makes clear the futility of CPR in the dying person.



Religion and Culture

Britain is very much a multi-cultural society. Many of the people you care for will hold religious, spiritual and cultural beliefs that are different from your own. These need to be both understood and respected in the final days of their life. To achieve this, you should discuss the topic with their family members who will be able to offer help and guidance in carrying out the person's wishes. Discussed below are some of the requirements of the most common religions and cultures.

Buddhism

- Buddhists believe in reincarnation. They believe the soul of the deceased will be reborn until they receive enlightenment.
- The first 1 to 7 days are the most important for final and funeral prayer.
- Buddhists are usually cremated.
- Prayers are said weekly, during a 49 day funeral period. It is believed that during this time the prayers will help awaken the deceased spirit to the true nature of their death.

Catholicism

- Catholics believe death is the start of everlasting life promised by Christ, and that the soul of the deceased goes on to the afterlife.
- The funeral service is called the Mass of Resurrection. After the funeral there is a final farewell at the graveside.
- Although the church encourages Catholics to be buried, cremations are now accepted. In this case, the ashes must be buried, not scattered or kept by the family.
- Eulogies are not allowed during the service, but may be said at a wake.
- The church community support mourners through funeral mass.

Hinduism

- Hindus believe that death is part of the continual cycle of birth, life, death, and rebirth. They believe that the soul of the deceased goes to another body when they die.
- Hindu's usually choose a cremation. In preparation for this, the body is bathed, laid in a coffin, adorned with sandalwood paste and garlands, and wrapped in white cloth. During the cremation the body is carried three times counter-clockwise around the pyre, then placed upon it.
- Although Hindu scriptures advise against excessive mourning, there is no specific time scale given for this.

Once an person's spiritual and religious needs are identified, these should be incorporated into their Advance Care Plan and honoured in the event of death. Spirituality, or something which makes a person's life complete, should also be incorporated into their Advance Care Plan in order to make it personal to them. This could be something they particularly enjoyed and can include things pertaining to their favourite sport, music, or pastime.

Islamism

- Muslims believe that there is another world after death. Practising Muslims prepare for this world during their life.
- Muslims must be buried according to Islamic law.
- The body is bathed and wrapped in a plain cloth called a kafan.
- Mourners gather together and offer prayers for the forgiveness of the deceased (Janazah).

Judaism

- Jews believe that death in this life will eventually lead to resurrection in a world to come.
- The dead are buried as soon as possible.
- The body is purified by washing and then dressed in a plain linen shroud. The casket remains closed after the body is dressed. As a sign of respect, the body is watched over from time of death until burial. A prayer is said in honour of the dead.
- Following the burial, there is an intense seven day mourning period called Shiva. People often wear a black ribbon as a symbol of grief, and cover mirrors.



Probabilities of Life Expectancy (POLE)

Probabilities of Life Expectancy is an End of Life Care tool developed to identify the stage of life a person is at. As their health declines, their needs will naturally increase and must be managed effectively.

Once implemented, POLE triggers specific support and promotes person-centred approaches to managing the identified needs. In turn, this increases the chance that the individual obtains quality care and comfort, as well as a dignified death.

Unlike other tools, POLE focuses on a person's changing needs, rather than just giving a timescale of life expectancy. Using this tool will help you determine the type of care required to ensure that the person's current health needs are met. We believe this is an important part of End of Life Care and helps maintain high standards of care to the very end.

Use the experience of key staff members

As always, teamwork is vital. So it's a good idea to sit down with several key members of staff to determine the stage of life each person in your care is at. Regular monthly meetings are ideal, but should naturally be more frequent if a person's health is deteriorating. Details of the meeting should be documented in their files. Examples of how to determine the stage of life of each individual you support are given below:

The stages of POLE are as follows:

- **Optimum Health** The person is of optimal health taking into account their physical, emotional and mental health. It describes the health goals a person can realistically achieve to be at their personal best.
- **Progression of disease which no longer responds to treatment** The person no longer responds to treatment of an illness and test results confirm deterioration. The person's needs will increase, sometimes rapidly.
- **Congenital abnormalities that affect life expectancy** This relates to conditions that are present at birth, as a result of hereditary or environmental influences, such as epilepsy, cerebral palsy and Down's Syndrome etc.
- **Caring at the end of life** The person is displaying symptoms of being in the final stages of their life.
- **Life threatening conditions that respond to treatment** The person has an illness or condition such as heart failure, diabetes, HIV/Aids or cancer. However, their illness is successfully being managed by treatment.

Once you have determined the stage of life the person you support currently appears to be at, we recommend the following actions:

Optimum health

- Introduce End of Life care to the person, family members and staff.
- Discussions around advance care planning should begin as soon as possible, ideally on admission. Plans should be put in place and reviewed on a regular basis. This way, if the person you support unexpectedly dies, the plans are there for you to follow.
- Liaise with GP to monitor the person's health status and mental health wellbeing, preferably on a quarterly or 6 monthly basis.
- Promote a holistic healthy lifestyle identified from the person-centred plans for the individual.

Congenital abnormalities that affect life expectancy

Follow the guidelines above, plus those below:

- Liaise with the person's specialist support network, such as epilepsy specialist if the person has epilepsy, to monitor identified health needs.
- Complete and review all health care plans and do an annual OK health check.
- Allocate a member of staff to coordinate the care package and to liaise with the person's family.
- Conduct regular reviews of medication.
- Provide training for staff to meet the health needs of the person. An example of this is diabetes training.

Life threatening conditions that respond to treatment

Follow the guidelines above, plus those below:

- Link with specialist services who can provide extra support and guidance.
- Review health care plans and risk assessments.
- Provide adequate equipment to continue to meet the person's changing needs or anticipated needs, such as slings and hoists.
- Promote effective communication and ongoing support for families and carers.
- Ensure everyone is involved in all decision making processes



Progression of disease which no longer responds to treatment

- Details of the person's condition should be passed on to local End of Life services and out of hours services sensitively.
- There should be increased contact with GP and district nurses.
- Provide practical care assistance and promote the person's independence with support for self-help skills and personal care tasks that help maintain their comfort and dignity.
- Encourage meaningful connections and communication with family members.
- Offer family guidance on any aspect of their relative's condition and bereavement to support and prepare them for their coming loss.
- Confirm the primary decision maker who will manage the information and coordinate family involvement and support.
- Respite care can be offered. This could involve a support worker sitting with the person, or a short stay in a hospice if this service is offered.
- Utilise local hospice services.
- Identify any further training requirements for support workers and enable them to participate in such training.
- If the person is a child, the information should be honest and age appropriate.
- Ensure any spiritual needs are met by using their Advance Care Plan.

Once you have identified that a person is deteriorating, there are a number of different things that may happen. These are discussed in the following section, *Deterioration of an Individual*.

Case Studies

The following are examples of people who would be at different stages of life, as described by POLE.

OPTIMUM HEALTH

Mary is a 63 year old female with a learning disability. She has no health conditions and her vital signs are all normal. She is mobile, and is of average weight and height. If Mary was to die suddenly it would be a shock to staff and her family. Therefore it is probable she is of **optimum health** and the guidance on this section should be followed.

CONGENITAL ABNORMALITIES THAT AFFECT LIFE EXPECTANCY

James is a 22 year old male with a learning disability and Down's Syndrome but is otherwise relatively healthy. However, due to the likelihood of premature death in people with Down's Syndrome, plus complications of his condition which may affect his health in the future, it would be wise to follow the guidance on **congenital abnormalities that will affect life expectancy**.

LIFE THREATENING CONDITIONS THAT RESPONDS TO TREATMENT

Michael is a 45 year old male with a learning disability and epilepsy. Despite taking several different types of epilepsy medication every day, he still suffers seizures almost daily. There have been instances in the past 12 months where he has gone into status epilepticus. This is an epileptic seizure a person does not recover from, often needing PRN medication to bring them out of it. He has required emergency medication to stop this. In any person with epilepsy, there is also a risk of SUDEP (sudden death in epilepsy). Due to these factors which affect his everyday life, and the fact that his medication is managing his seizures as effectively as possible, it would be beneficial to follow the guidance on **life threatening conditions that responds to treatment**.

PROGRESSION OF DISEASE WHICH NO LONGER RESPONDS TO TREATMENT

Natalie is a 23 year old female with a learning disability and terminal cancer as diagnosed by her cancer specialists. Her care needs are increasing and she is slowly losing her independence. She is taking pain medication but all other treatment has been stopped by her GP. Due to these factors, it would be beneficial to follow the guidance of **progression of disease which no longer responds to treatment**.

Stage 3

Deterioration of an Individual



Once a person is approaching the end of their life, there are a number of things to be discussed by you and other healthcare professionals who support the individual.

These are:

- **symptom control**
- **resuscitation status**
- **reduced trips to hospital**
- **out of hours continuity**
- **PRN as and when required medication and 'just in case' medication prescribing (anticipatory)**
- **supporting relatives**
- **End of Life support**

Symptom Control

Once someone starts to display symptoms of dying or their illness begins to get worse, it is important these symptoms are controlled effectively. At this stage, the GP should be involved with the person's care and you should be making regular contact with them. They will be able to assess what medication will benefit the person and give you advice and support on how to continue to meet their needs. A community nurse may also be able to offer support and guidance, so it's a good idea to refer a person to the community nurses team.

Document the symptoms

It is also worthwhile to start documenting the severity of a person's symptoms, and whether they are using as required (PRN) medication to control them. This information can then be passed on to the GP, who can then assess whether their medication needs to be reviewed and perhaps a different type of medication prescribed. They will be able to advise you when to give the medication, how much they can take in a 24 hour period, plus what side effects to look out for.

Resuscitation Status

Once an person's health starts to deteriorate, it is time to think about a DNACPR order, if one isn't already in place. Once a DNACPR order has been put into place, it is important to discuss this with all staff members who work with the person. Because DNACPR is a legal document, it *must* be followed by all staff, and it is important that all staff are aware of this.



Reduced trips to hospital

Once a person is known to be coming towards the end of their life, it can be worrying for staff when their health takes an unexpected turn. This may mean the person gets taken to hospital more often than usual – and sometimes for things which can be treated in the home.

Once a person has been diagnosed to be at the End of Life, there is often very little the healthcare professionals in a hospital can do to help. The medication alone will often be making the person as comfortable as possible in their final days. It is important to let the person you support have as dignified a death as possible. Sometimes going into hospital and having tests done may prevent this from happening.

It can also be distressing or tiring for the person to be taken to hospital, and it could make them more susceptible to other health problems, such as infections. As long as their pain and other symptoms are being managed effectively, and they have access to all the medication they need, a trip to hospital can often be avoided.

Don't be afraid to ask for advice

By this stage you should have regular contact with the person's GP or palliative care nurse, and they will be able to advise about any concerns regarding the person's health. It's a good idea to put plans into place so that staff know at what point they need to contact the out of hours team. This might be if a person appears to be in pain or if they are struggling to swallow food or fluids. The out of hours team will be able to determine whether or not a trip to hospital for the person is needed.

Most hospices have a 24 hour advice help line which is most useful if the person is already known to the palliative care team.

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Out of hours continuity

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If one of the people you support is admitted to hospital, it is important to ensure good communication with the ward. Due to staffing issues or costs, it may not be possible for a member of staff to be with the person at all times. However, it is important to know the progress of the person whilst they are in hospital so you should instruct one or two members of staff to make regular contact with the hospital, to gather information on the health of the person. This information should be documented and kept in the person's file, and can be used to update families about the condition of their relative.

Keeping regular contact with the staff on the ward will also be beneficial to the person, as you will be able to give them advice on their needs and support plans. They will also be able to ask for things the person needs, such as pyjamas, incontinence pads or toiletries.

'Just in Case' or 'Anticipatory' Medication Prescribing

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When a person is approaching their final weeks or days, it is appropriate for the GP to prescribe 'just in case' or anticipatory medication.

These medications are prescribed to manage a person's symptoms such as pain or seizures. It is worth having these medications in the home, ready to administer in the event of change in symptoms. Once an person is taking anticipatory medication, it is important to document this and analyse whether or not these medications appear to be working. By doing this you will be able to pass on any information to the GP or community nurse team, so that they can assess the efficacy of the treatment.

Take advantage of the community nurse team

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A syringe driver, which administers a constant, specific amount of medication over 24 hours, may be needed. They are particularly useful because they do not rely on the oral route to give medicines. If required, the community nurse team will come out each day to administer the medication, or provide your staff team with the relevant training so they can do this themselves.

The community nurse team plays a vital role in End of Life care. If any problems occur with the medical equipment it is important to contact them so they can come and resolve the problem.

Supporting Relatives

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Supporting the family members of a person living their final days is an important part of End of Life care. Practical advice should be offered as well as informed answers to any of their questions or concerns. Naturally this is a difficult time for relatives, especially if they were close to their loved one, and you and your staff team will need to be prepared for this. The level of support required varies from family to family, but you should try your best to offer as much support as they need.

Involve family and friends

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Involving relatives and friends in the various aspects of their loved one's final days can often be a comfort. For example, this could include meetings with doctors or community nurse teams. Of course, you may need to simplify some of the information for them, as sometimes this can be full of jargon that only healthcare professionals understand.

And if a person's family speaks a different language, it is important to use an interpreter so there is no breakdown or confusion in communication. Details of local counselling services or help lines may also be helpful to grieving families.

End of Life Support

It's never easy to determine exactly when a person is approaching their final days. However, there are a number of symptoms and side effects that may indicate death is not too far away. Shown below are some of the common ones for you and your support team to look out for, as well as guidance on how best to manage them in your home. Remember, every person is different and not all these symptoms will necessarily be present, nor indicate that death is close.

- **Sleepiness** – To combat this try to plan visits and activities when the individual is most alert.
- **Unable to swallow well or having no interest in food or drink** – Let the person choose when and if they want to eat or drink. Ice chips, water or juice may be refreshing if the person can swallow.
- **Loss of control of bladder or bowel** – Keep the person as clean, dry and comfortable as possible. Place disposable pads on the bed beneath them and remove when they become soiled.
- **Changes in breathing pattern or heavy breathing** – Breathing may be easier if the person is turned to the side and pillows are placed beneath their head and behind their back. A cool mist humidifier may also help.
- **Cold feet, hands, arms or legs** – Warm the person with blankets but avoid electric blankets or heating pads as these may cause burns.
- **Complete loss of consciousness** – Many people are still able to hear after they are no longer able to speak, and some experts think that hearing is one of the last senses to go. Encourage both staff and family members to continue talking to them.
- **Disorientation or confusion** – Speak calmly to help keep the person relaxed. Let them know when you enter the room, who else is also there, and talk about what is happening around them.

Informing family and friends

It can be very difficult to watch a person go through these changes. However they are natural symptoms of dying and by this stage you'll have regular contact with palliative care nurses who will be able to help you determine if they have reached their final stages of life. When this occurs, it's time to inform family members or next of kin so that they have the opportunity to be with their loved one in the final days.

At this point, you should assess care plans and, if necessary, put new ones into place to ensure that the person's needs continue to be met. This may include changes to manual handling or bathing. You should also have regular contact with their GP who can assess the effectiveness of symptom control medication and make changes if needs be. For instance, this may include changing the route of medication, and discontinuing non-essential medications.



Helping to deal with the person's emotions

The person may also experience a variety of emotions during the final days of their life. This often varies from person to person, dependent upon their age, family situation and the experiences they have had in life. Some people may want to settle 'unfinished business', such as:

- resolving any problems in family relationships
- visiting certain places
- buying gifts for their loved ones
- sorting out their belongings and giving special items to members of their family
- ensuring a will is in place
- seeing a religious leader

It is important to help the person with any of these requests. If the person you support is unable to discuss these things with you, it's a good idea to hold a 'best interests' meeting with staff members or their family. This way you can discuss a favourite place they might want to visit for one last time, or arrange for the relevant religious leader to give a blessing.

It also helps to prepare other people you support for what is happening. They may be aware that something is happening but a little confused by it all. Explaining the circumstances often helps alleviate any concerns they may have. This could involve providing them with easy-to-read literature or the use of pictures for reference.



Preparing staff members

It may be difficult for staff members to accept that the person is dying, and you need to manage this in a sensitive way and provide them with support. For instance, they may have built up a close relationship with the person over several years and it is important to acknowledge this. So give them time out during the shift to gather their thoughts. And, of course, allow them to say their final goodbyes too. Of course, each staff member is an individual and will react in different ways. So it's a good idea to have a meeting with each one to determine their level of need.

During a person's final days, you may feel that nothing you do is right and that you are not helping the person. However just being with them and making them as comfortable as possible is the best thing you can do and will be appreciated. Keeping the person informed and being open and honest will maintain the relationship and trust they have built with you over the years. Spend time with them doing things they enjoy, such as listening to music or watching TV. This will make them feel safe and secure and provide a good deal of comfort for all concerned.

The Final Moments of Life

The final moments of life are often very peaceful. Breathing becomes irregular and slows down dramatically. The stomach muscles control the person's breathing rather than the chest, and you will see it rise and fall with every breath they take.

Once an individual has got to this stage, it could be just a matter of minutes or maybe even a few hours before they take their last breath. Everyone is different. It is important that someone is with the person during this time, because even though they are dying they may still sense your presence, which will be comforting to them.

Other people may also wish to say *their* goodbyes at this time. So consider their needs too and allow them time with the dying person if it is felt appropriate.

Stage 4

Death of an Individual



Responsibilities at time of death

If you think that a person you support has died, you must do one of the two steps below:

- **IF THE PERSON DOES NOT HAVE A DNACPR IN PLACE CALL AN AMBULANCE (999) AND START RESUSCITATION**
- **IF THE PERSON DOES HAVE A DNACPR, DO NOT CALL 999, CALL 111, THE INDIVIDUAL'S GP, OUT OF HOURS GP OR DISTRICT NURSING TEAM.**

Supporting after Death

Naturally, it can be very upsetting for staff when a person dies. However it is important to stay calm and be professional as there are a number of important things which now need to be done.

Firstly, if you think that someone has died, you should phone their GP right away and explain the circumstances. If it is out of office hours or the person does not have a GP then you need to phone either 999, the out-of-hours GP service, or the district nursing team.

It is important to leave the area undisturbed. A GP or another qualified medical practitioner will come to verify the death, the person's body will be taken away, and you will be issued with a death certificate. If the family are arranging the funeral the death certificate should be given to them so they can register the death. Otherwise you should do it.

All of the person's medication and medication records should be kept for a minimum of 7 days, in case there is a coroner's inquest.

Contacting family and friends

You should inform the person's family of their death as soon as possible. If you have a link contact you should contact them. Some grieving relatives take comfort in saying their last goodbyes to the deceased, or by talking to them or praying before proceeding to final arrangements. You should be prepared for this to happen.

It may also be appropriate to offer counselling services to both staff and family members, as well as any other individuals who use your services. Remember, people deal with death in many different ways.

Once a person has died, all the documentation should be ready so that the funeral can be organised. This is where the Advance Care Plan comes in handy since you will already know the individual's preferences and final wishes and should honour them as a sign of respect. For instance, ensure that any religious needs of the person are met.

After Death arrangements

Once a person has died, there are a number of things you may choose to do. Some of these are outlined below:

- Appoint a member of staff with a good relationship with the family as a point of contact. They can not only provide support to the family but also liaise over funeral plans or memorial services.
- Send a sympathy card and a wreath, or make a donation to the charity of the person's choice.
- Offer the family to set off to the funeral from the person's home.
- Offer the family the option of having the funeral tea at their relative's home.
- Support other people who live in the home to go to the funeral if they wish.
- Offer local counselling services to both staff and family as well as other individuals who live in the home.
- Identify a lead contact with the family and maintain contact with that person.
- Offer support to the family around the estate of the person
- Hold an annual remembrance service either in the home or in the grounds.

The next step

Once a person has died and their funeral has taken place, it is a good idea to sit down with your team to reflect upon and discuss the events.

For example, you might want to talk about what you did well as a staff team, or what you feel you could have done better. By analysing the standard of care surrounding the person's death, you may be able to implement changes the next time you face this situation. This will not only help you improve the standard of care given to other people, but also increase your confidence when dealing with End of Life care.

Ask loved ones for their feedback

Once the family have had time to mourn and grieve, you may wish to ask them for feedback about the care their relative received. You can do this by letter, or in person if you still have contact with them. Positive feedback is very beneficial for the moral of the care team as it reassures them that their work is appreciated and that they have cared well for the person. And, of course, any negative feedback is vital for helping you to improve future standards of care.

It may be difficult at first to get used to the home without the person around. However, time is a great healer and eventually it will become easier for you, your staff, and other people who live in the home. Knowing that you did everything you could to provide a 'good death' will help to prepare you for it happening again in the future.

Further Information

This document is part of an End of Life care Package for health and social care staff.

Other documents in this series include:

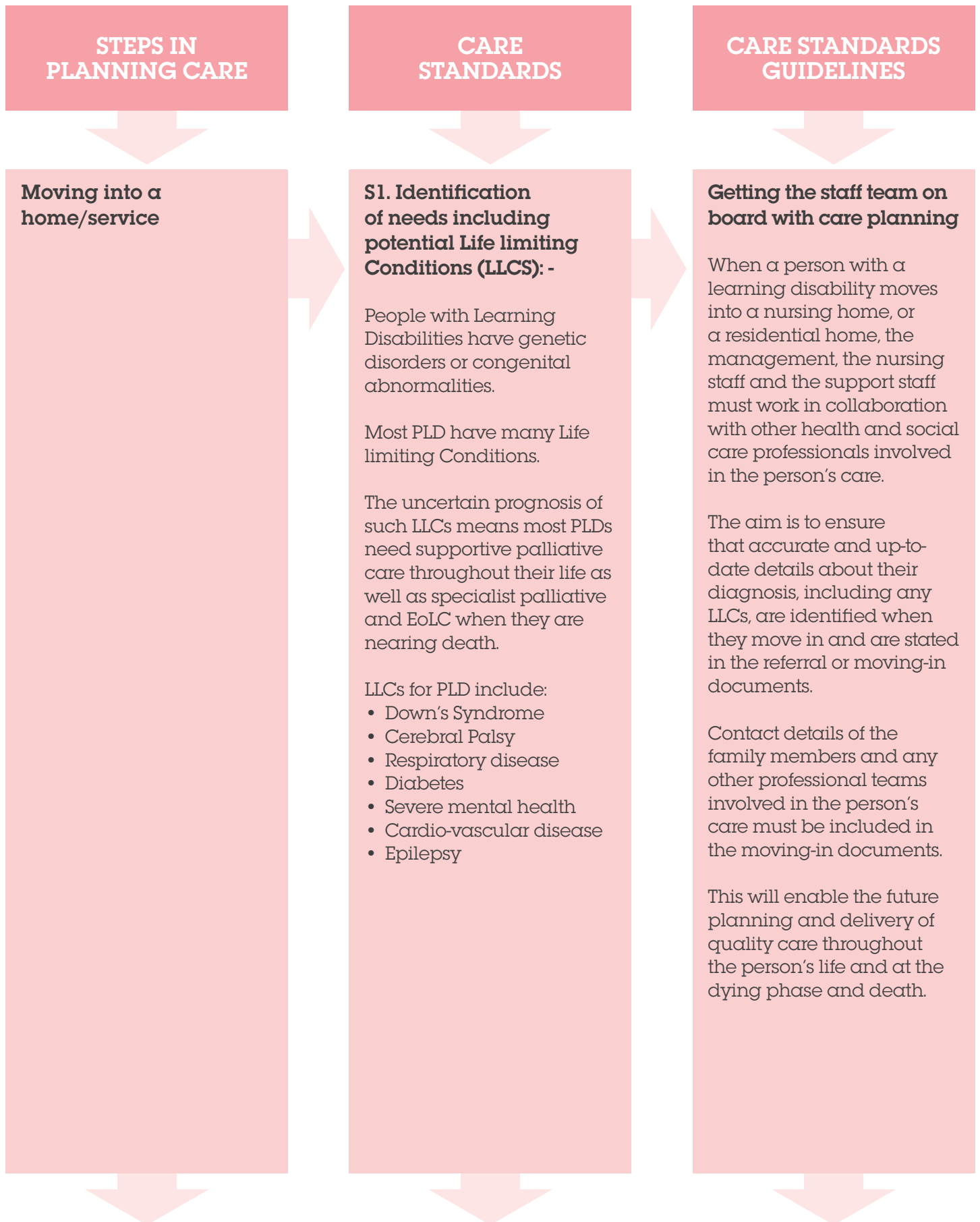
- **Probabilities of Life Expectancy**
 - **Standards**
 - **DVD**
 - **Training package**
 - **Probabilities of Life Expectancy leaflet**
 - **My Advance Care Plan (Easy Read)**
 - **Guidelines for implementing documentation**
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3

STANDARDS ON END OF LIFE CARE FOR PEOPLE WITH LEARNING DISABILITIES

Part of the comprehensive guide
for health and social care staff

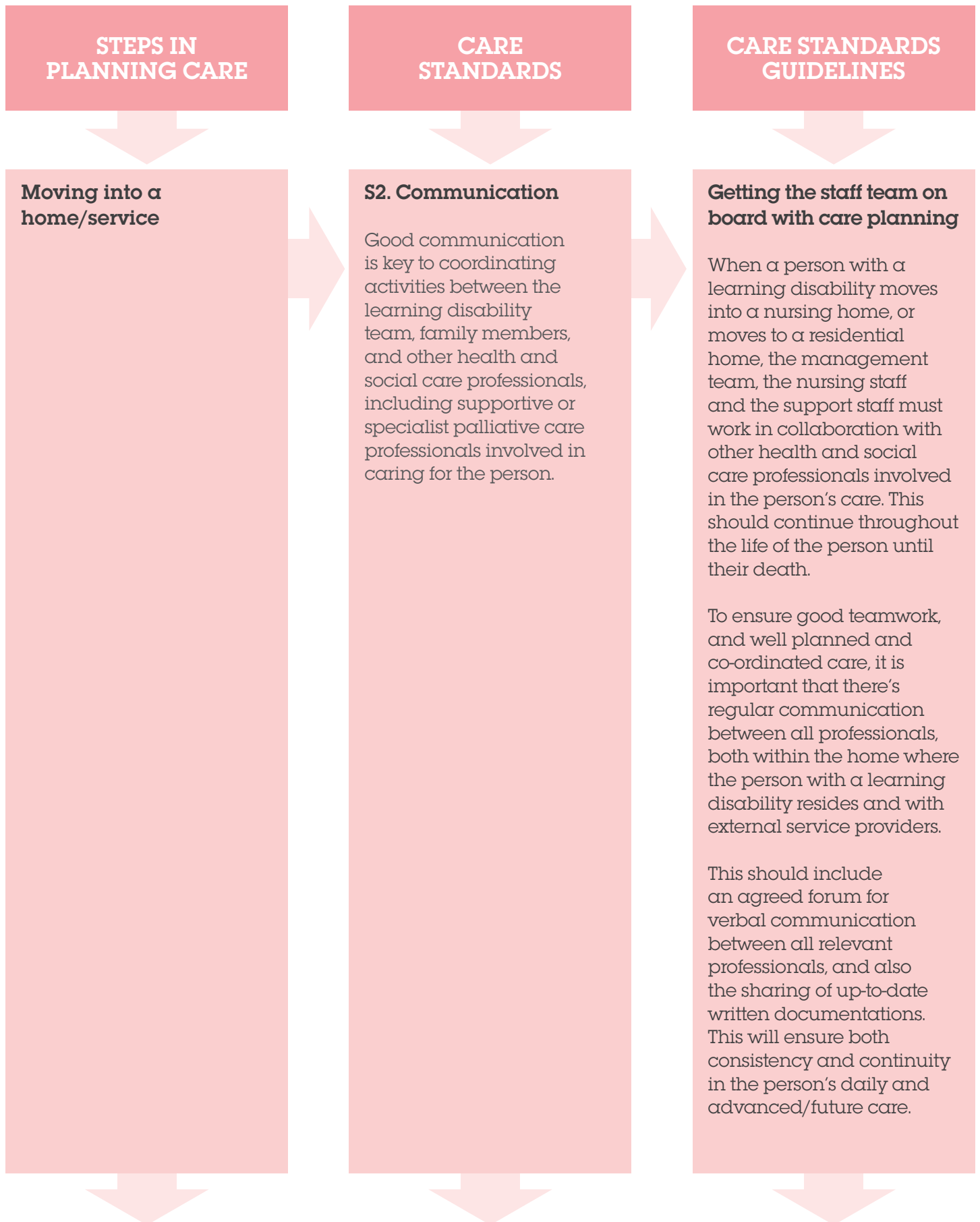
Standards on End of Life care for People with Learning Disabilities



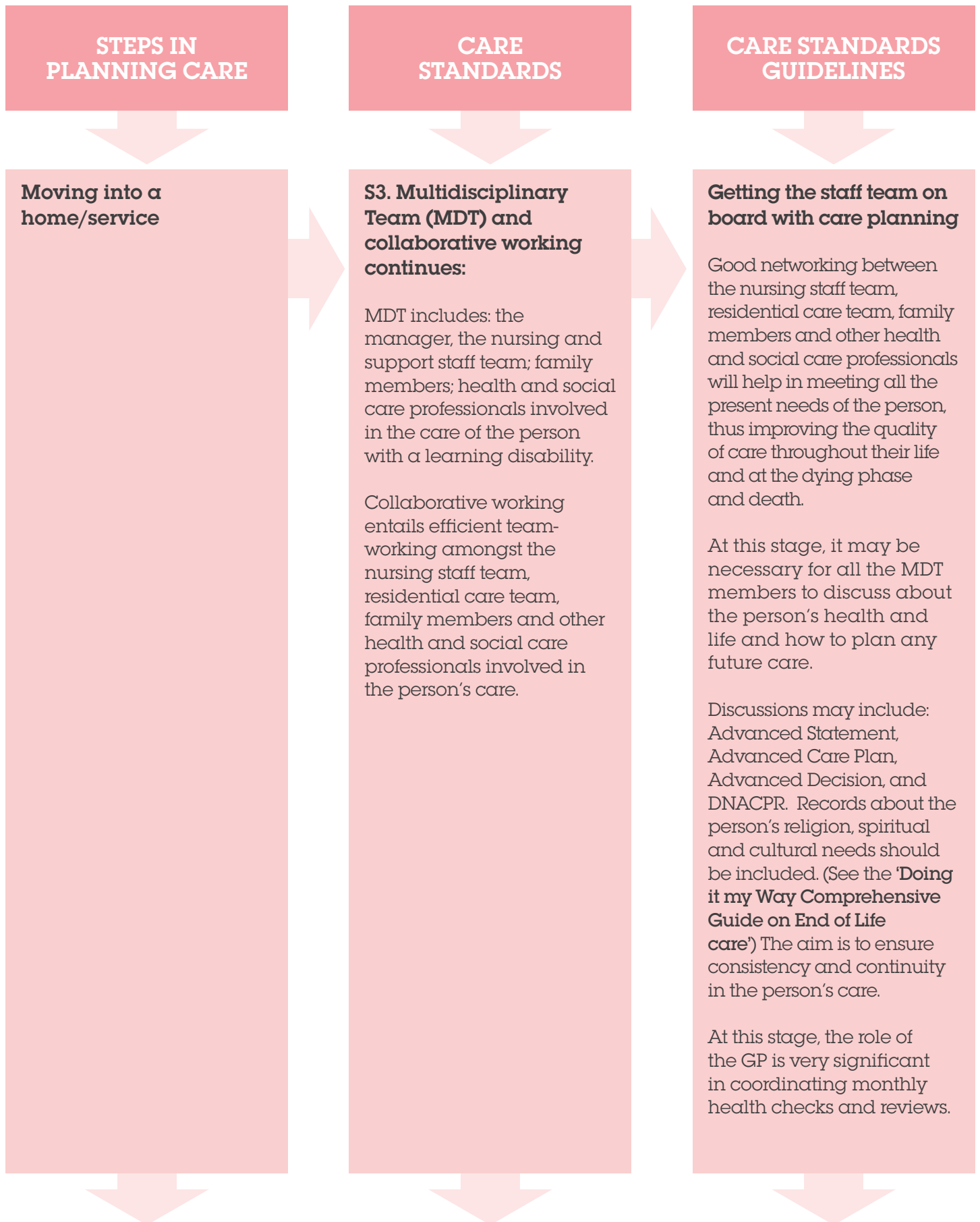
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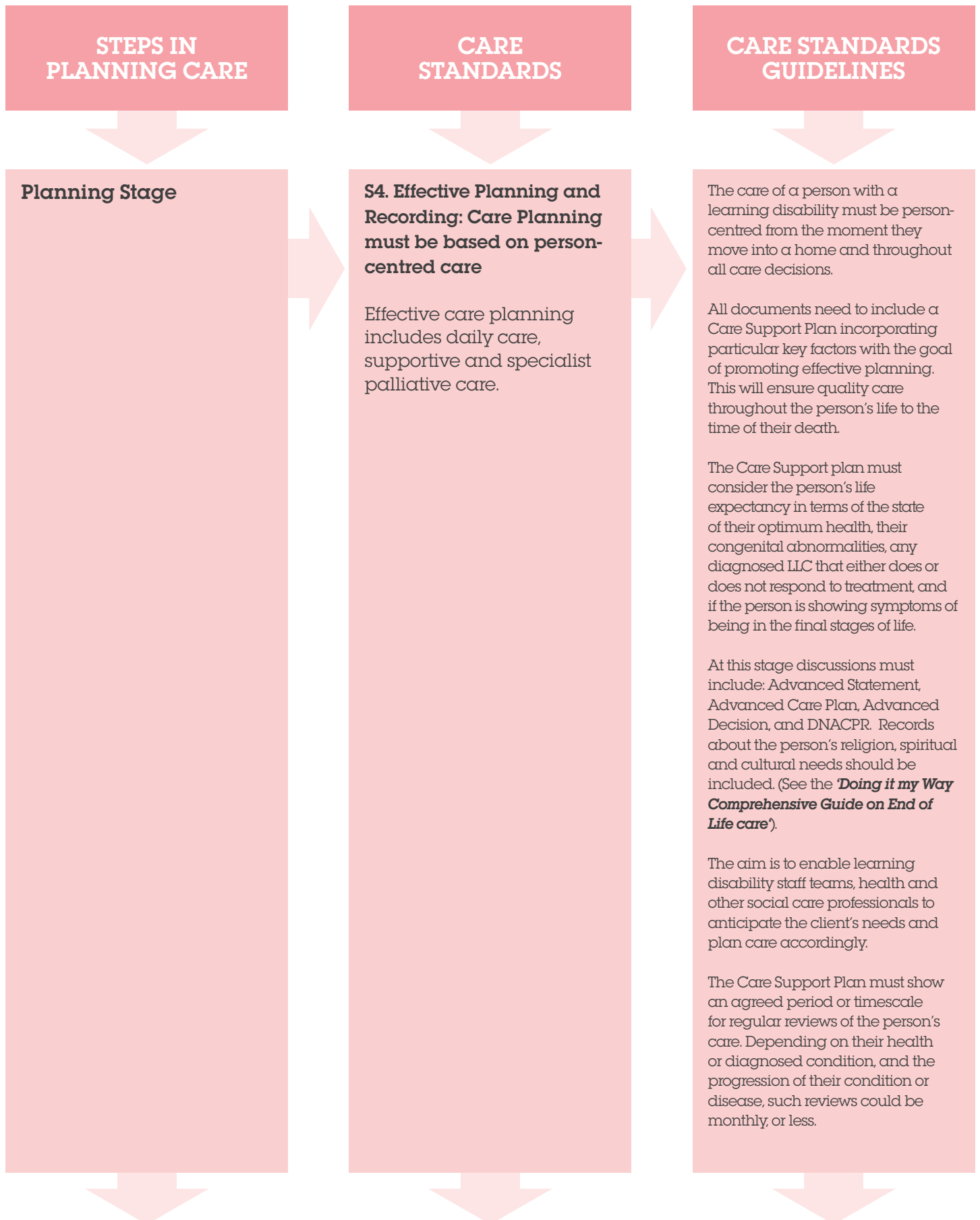
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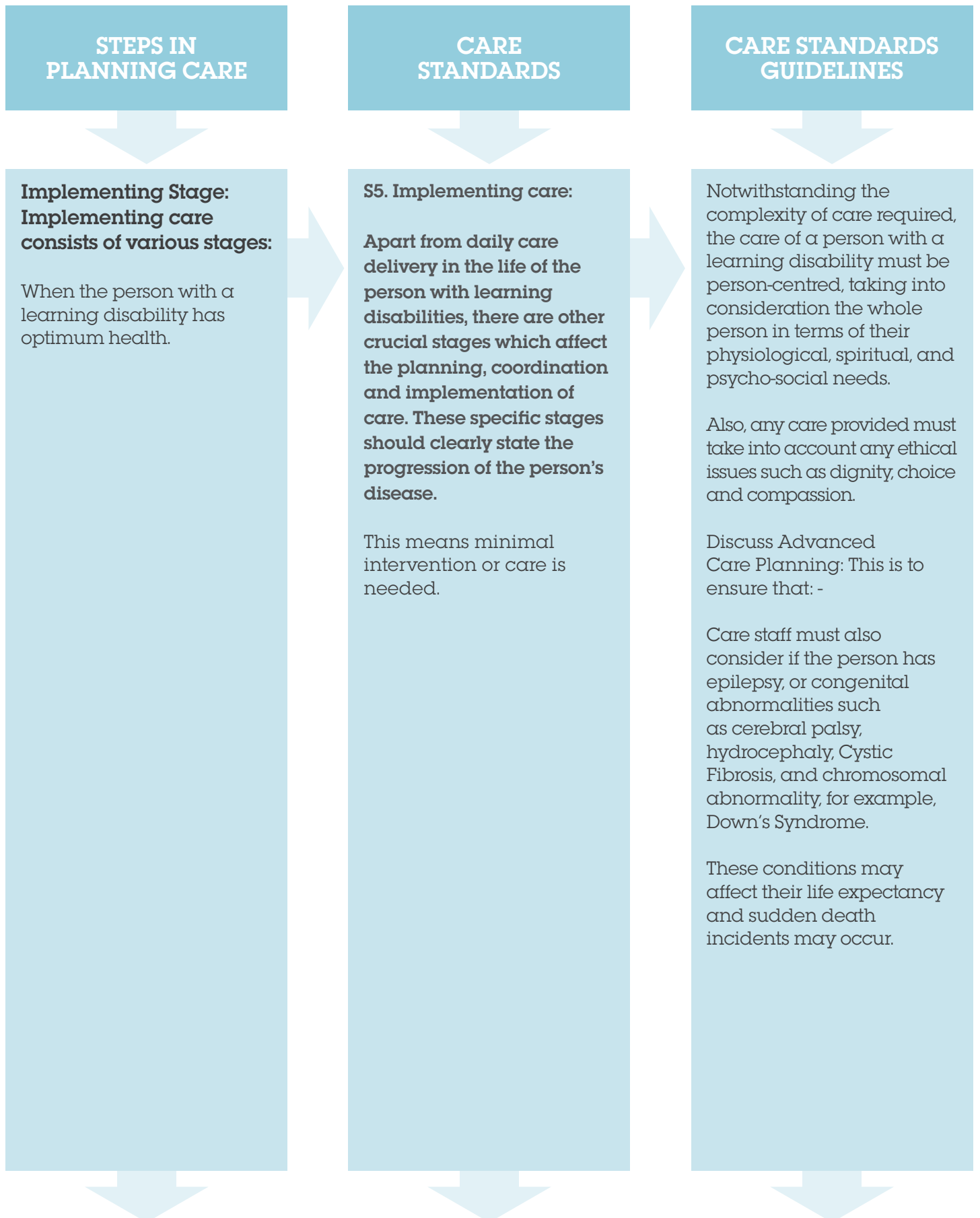
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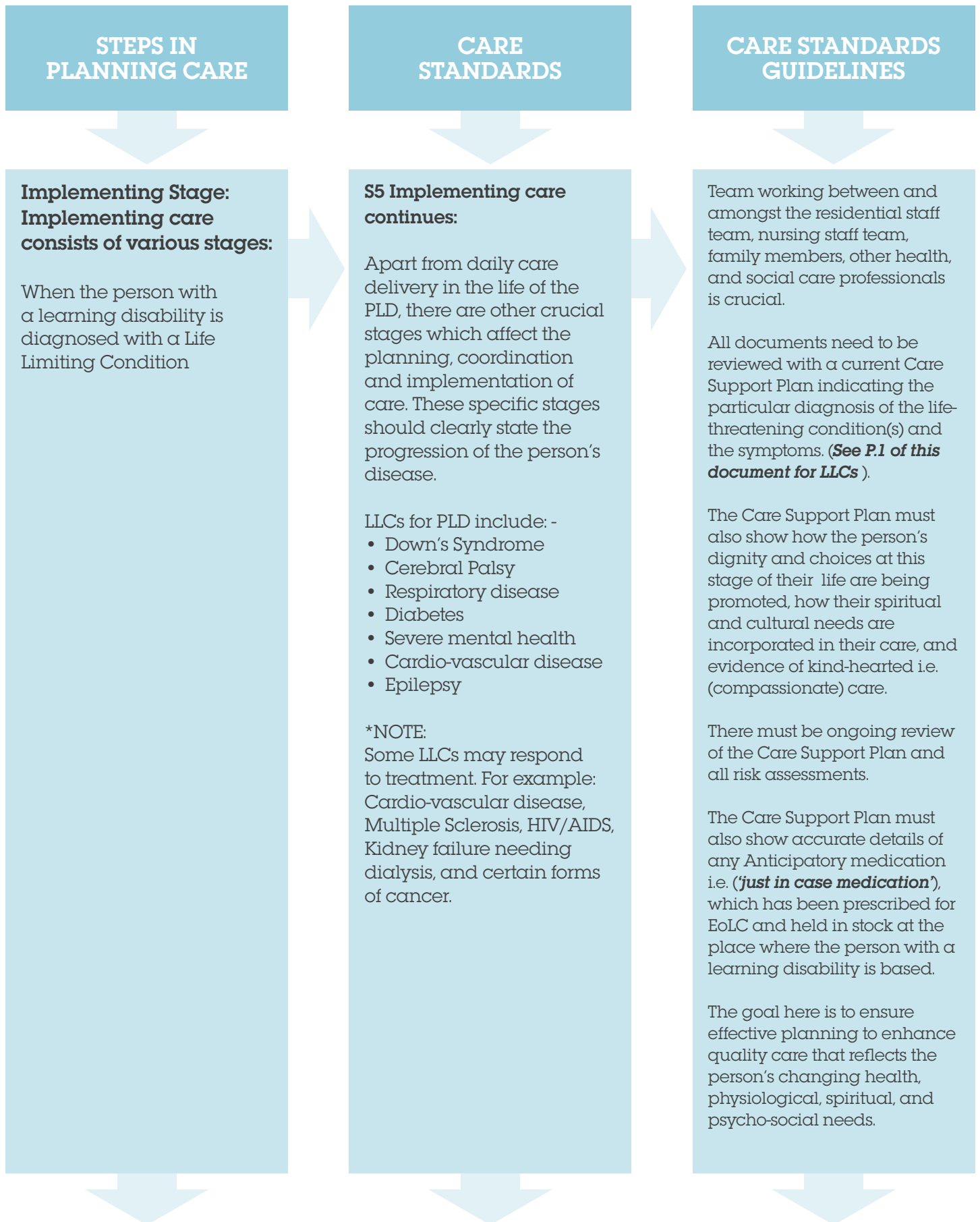
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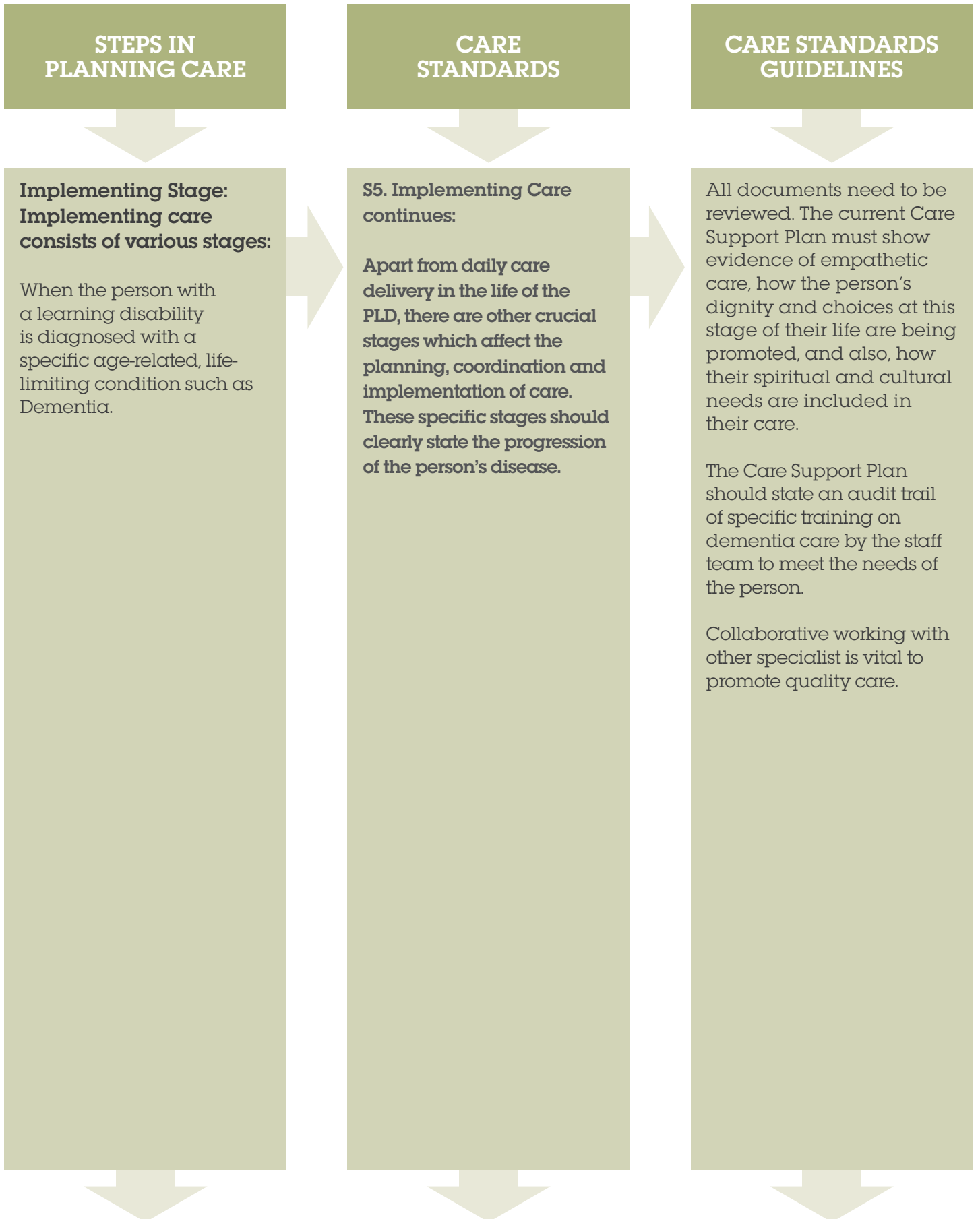
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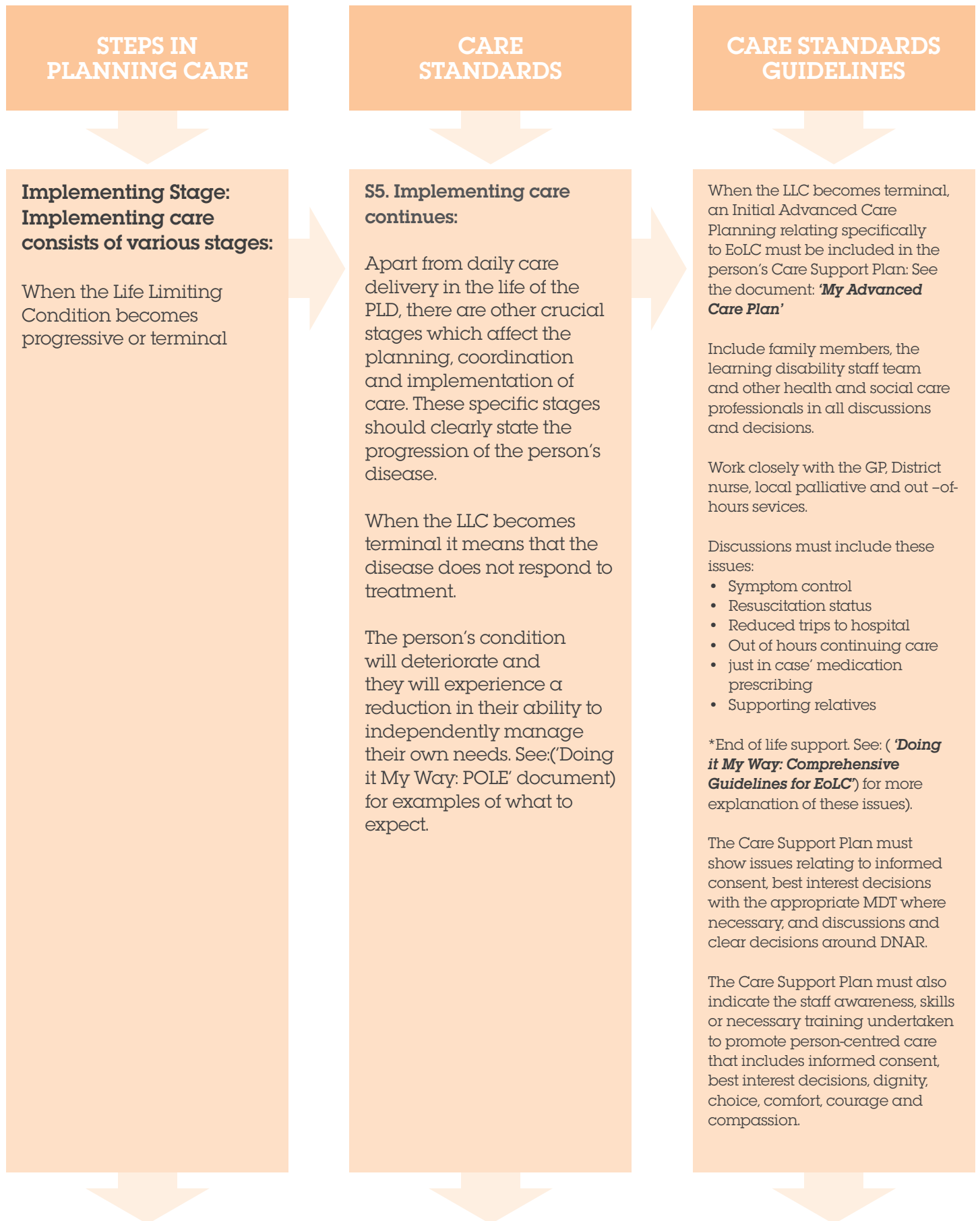
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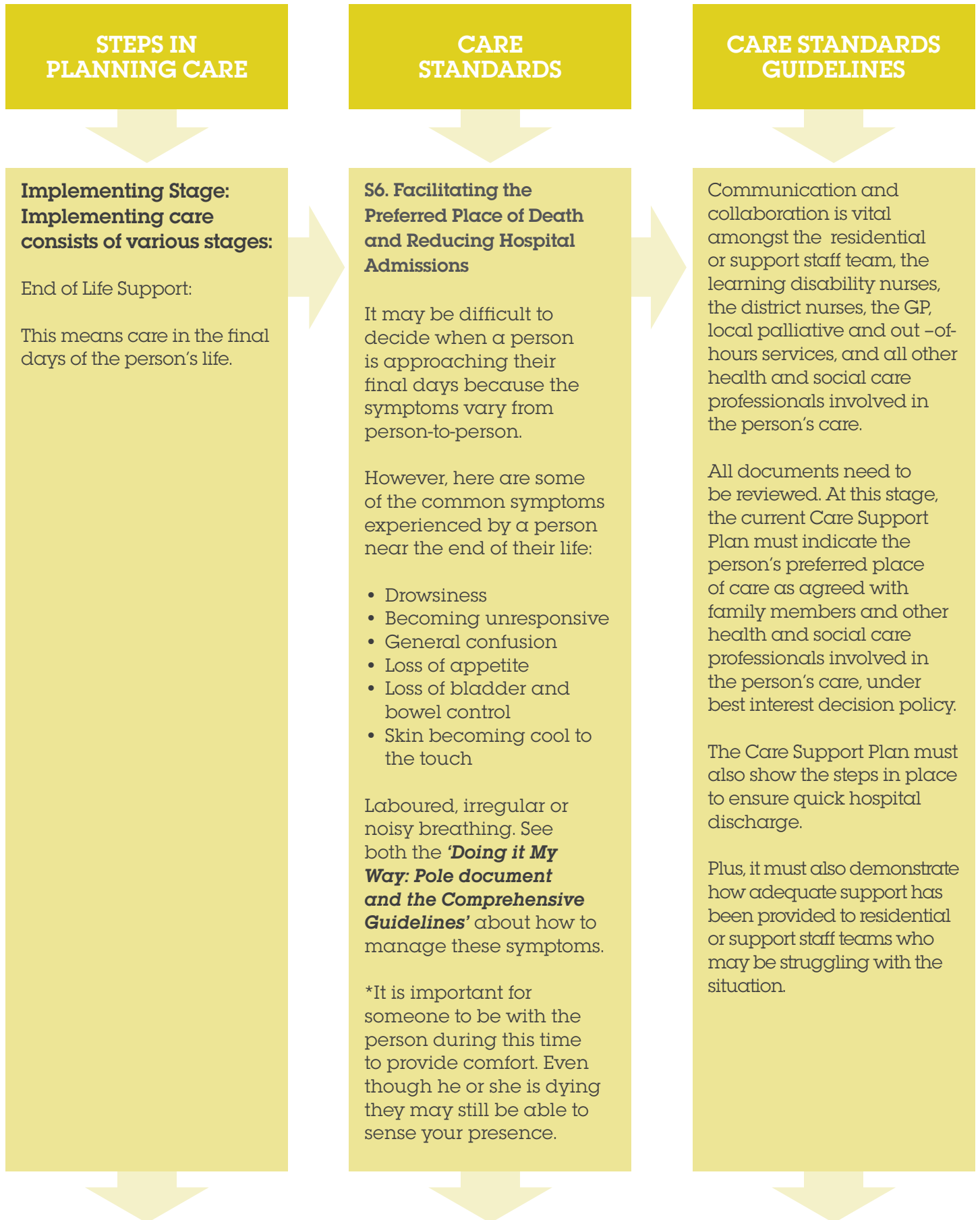
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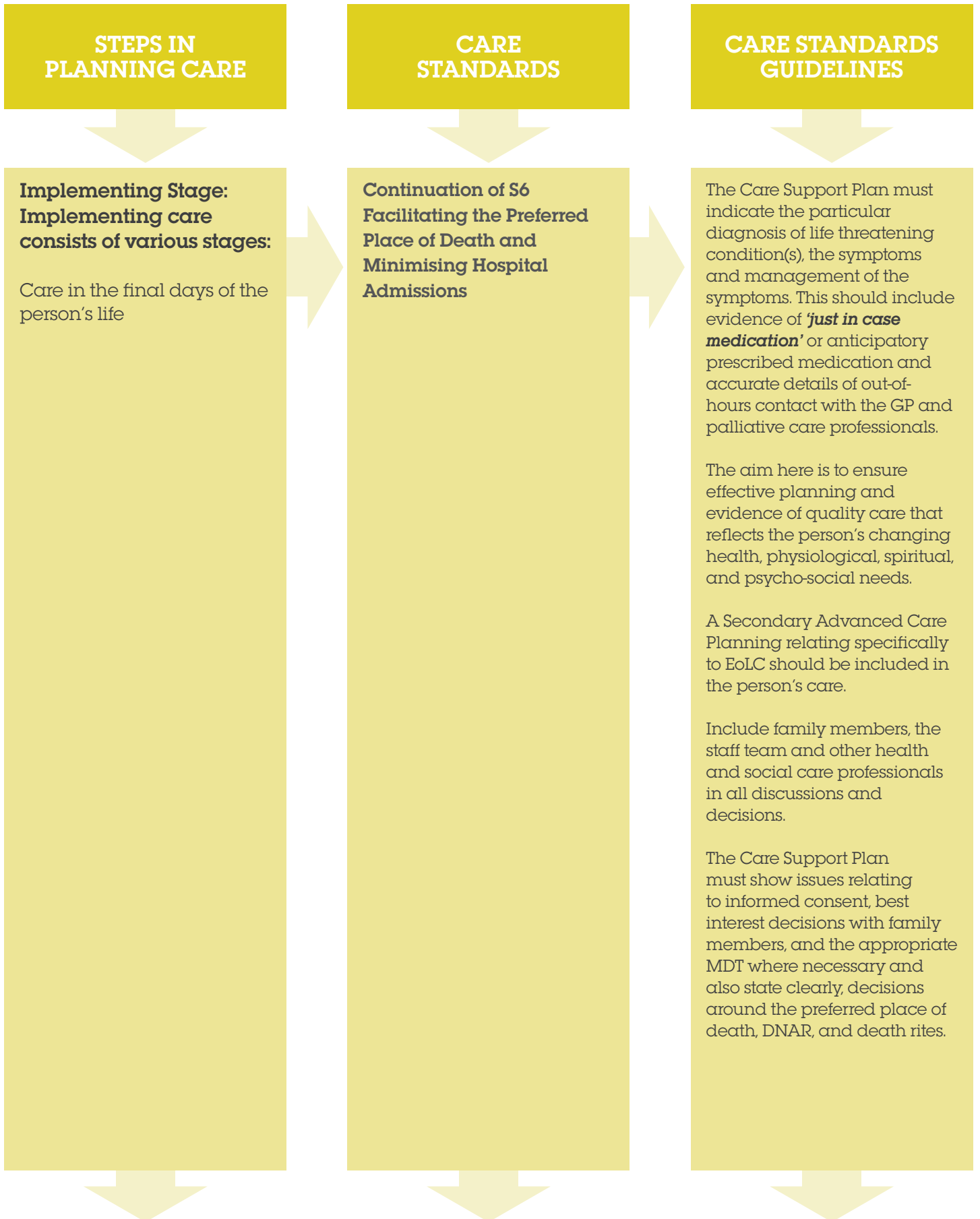
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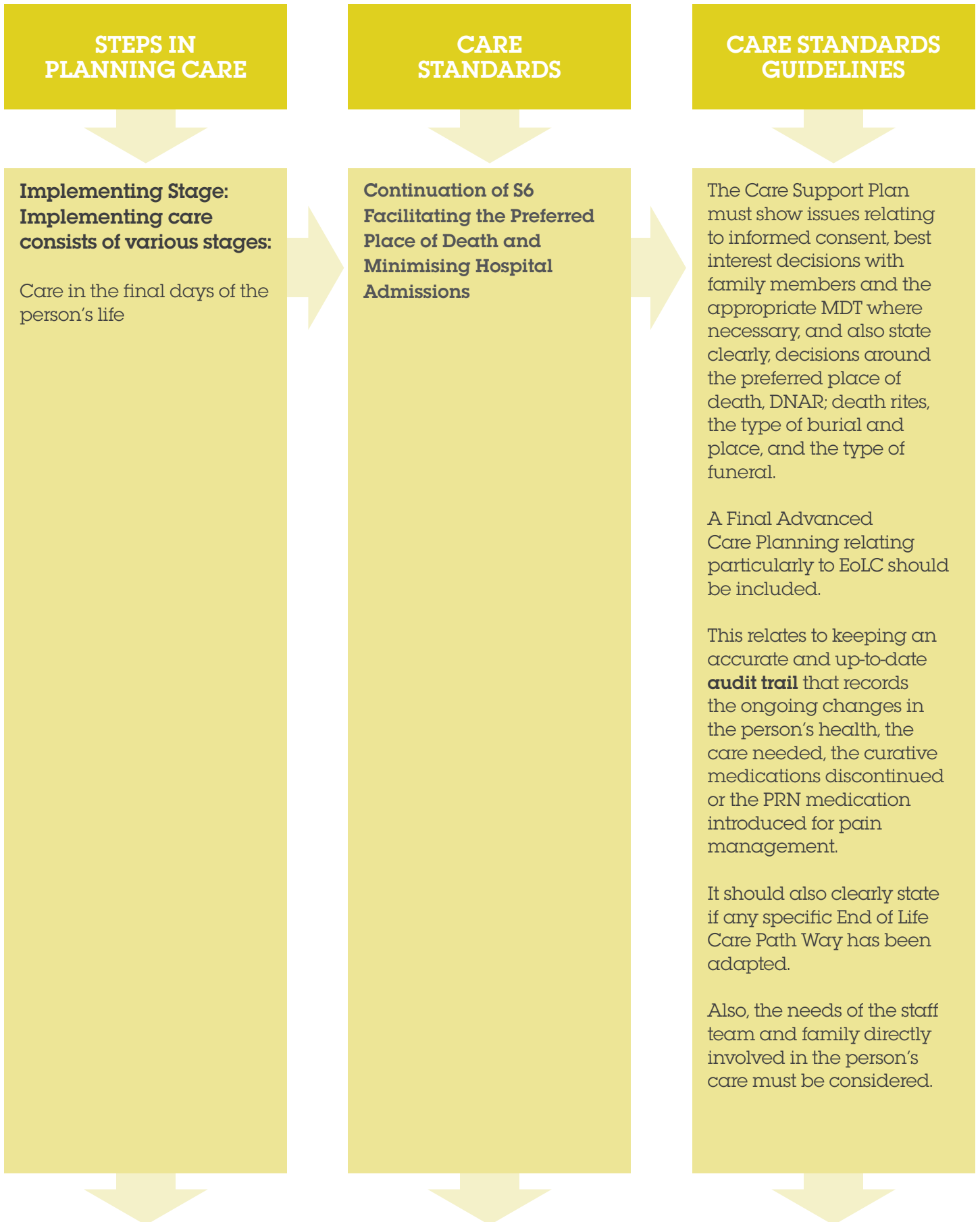
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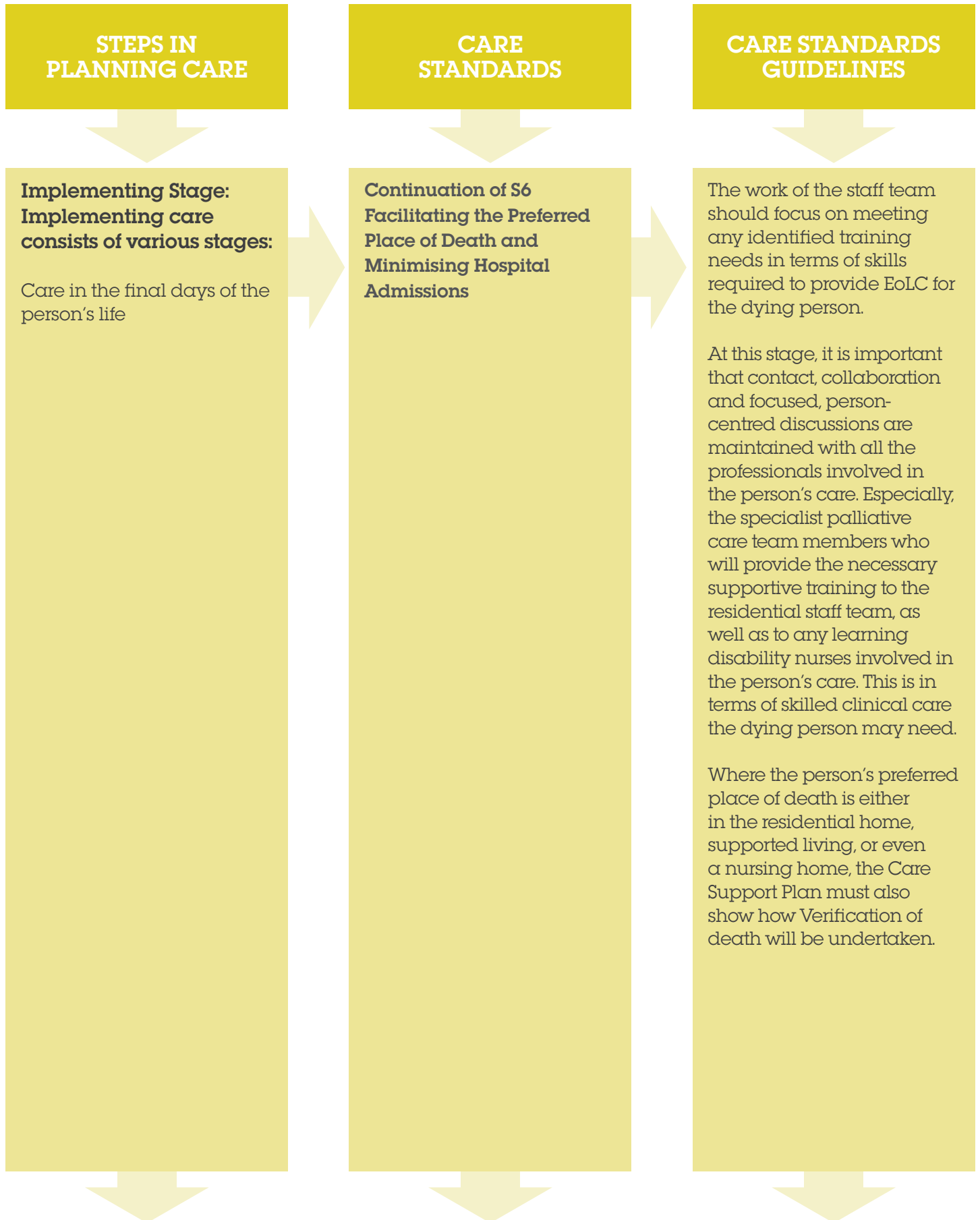
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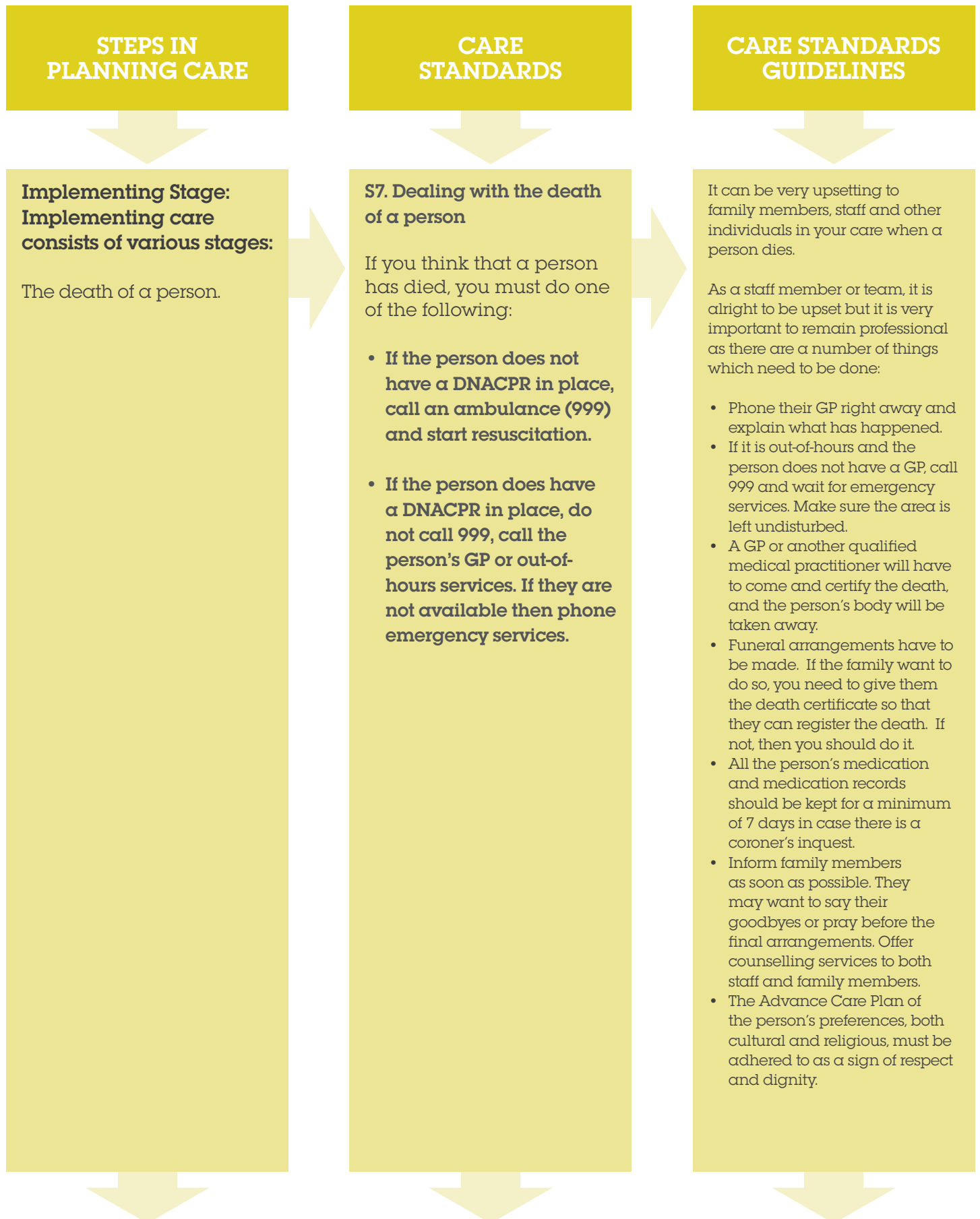
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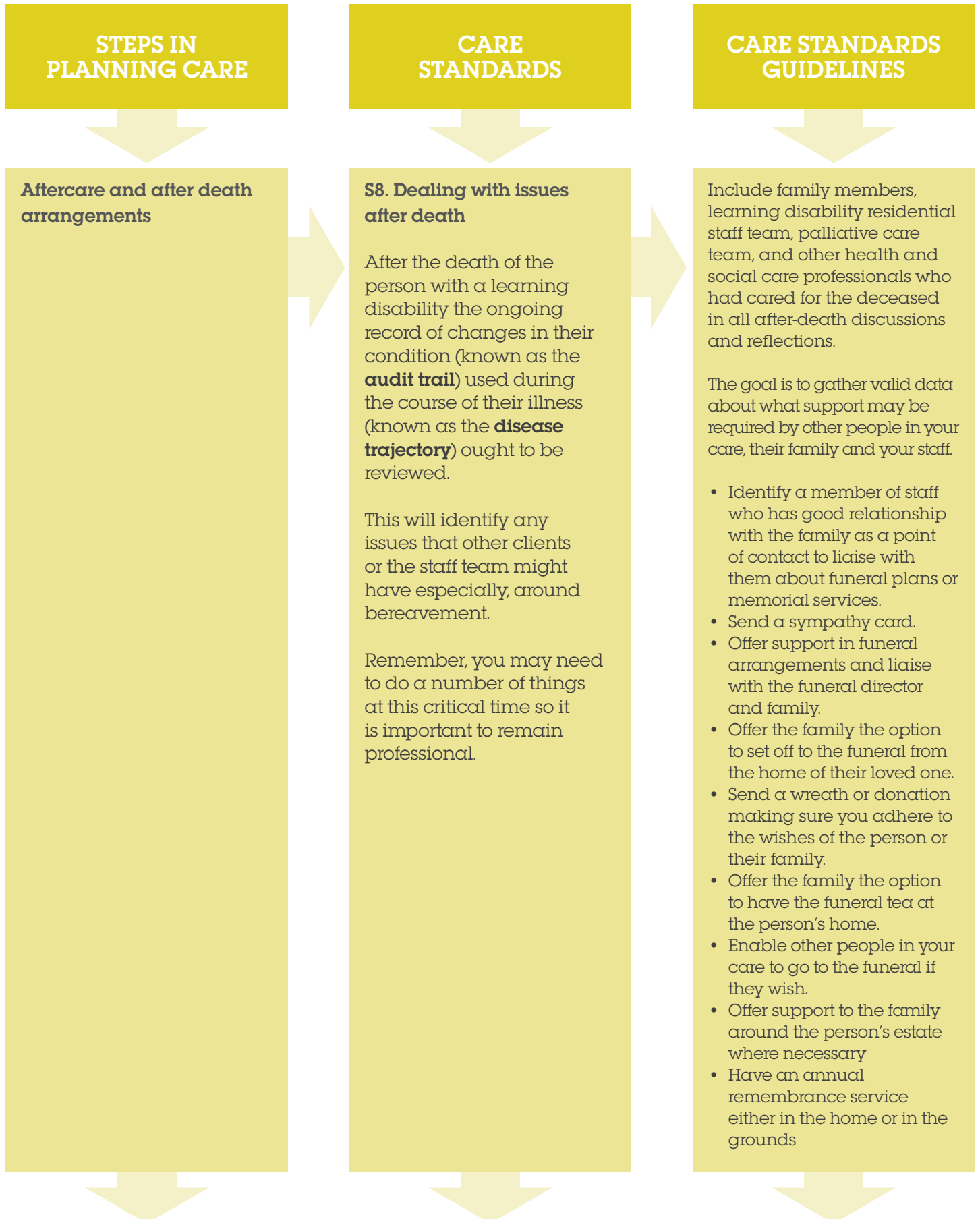
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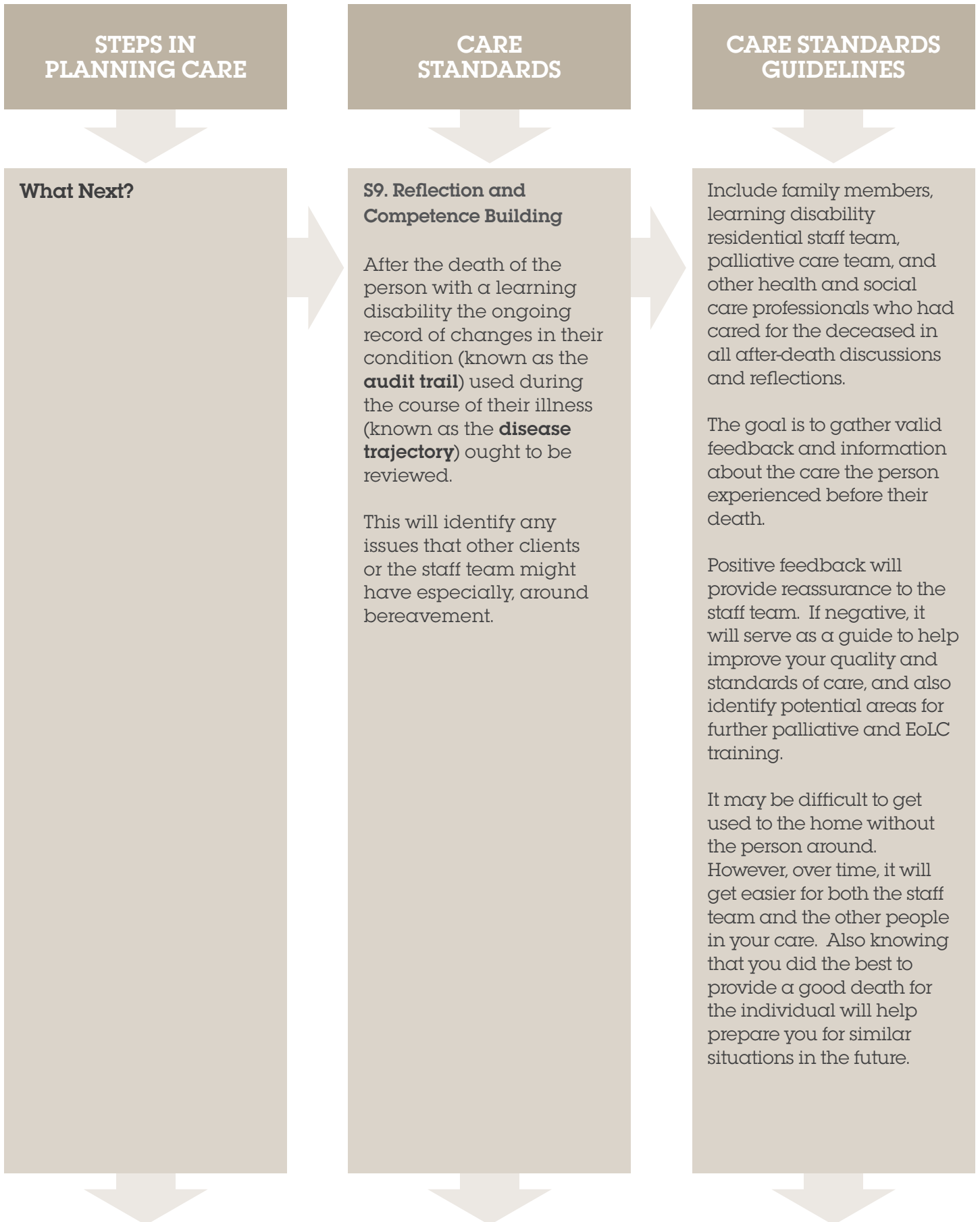
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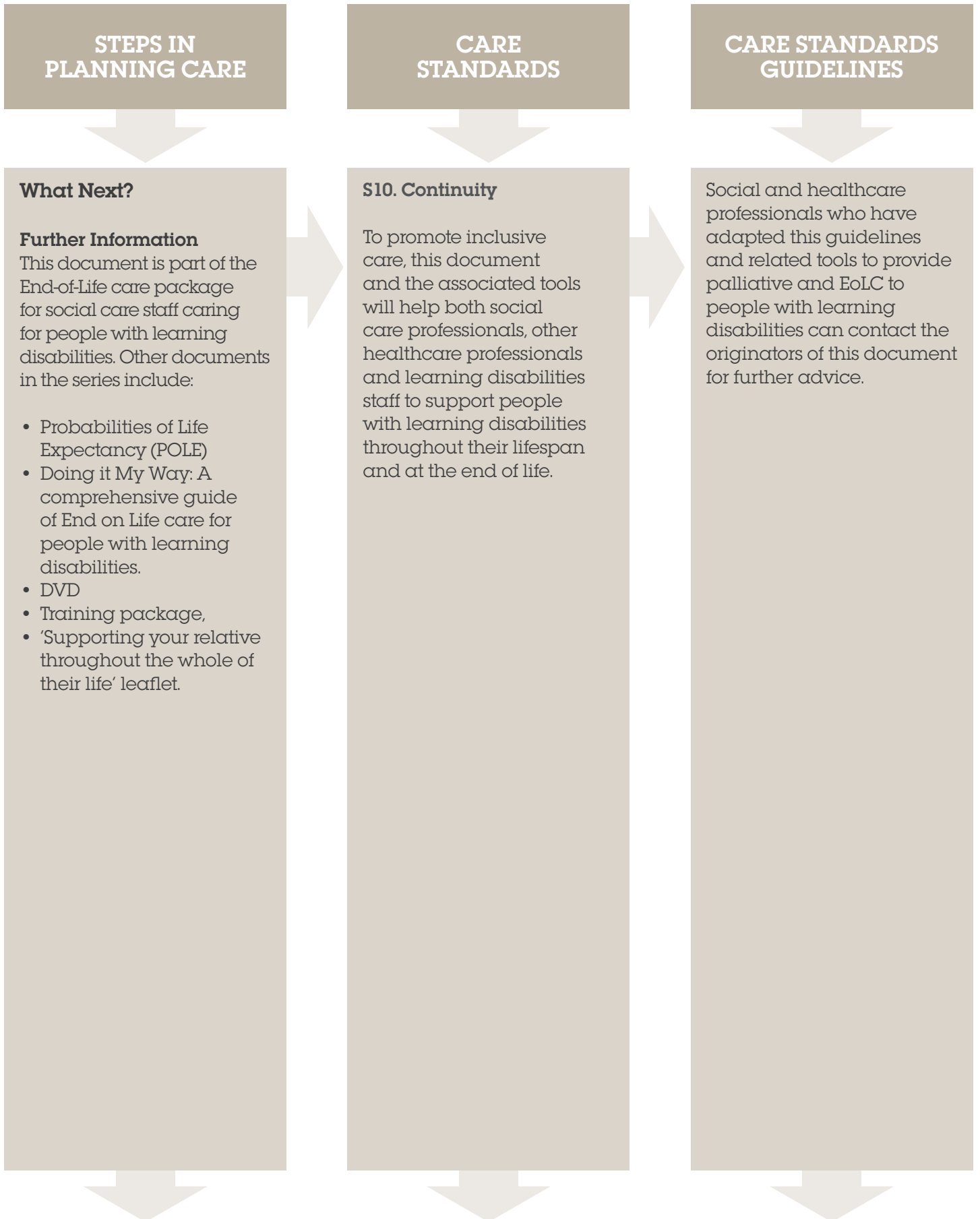
Standards on End of Life care for People with Learning Disabilities



Palliative and End of Life Care Standards for People with Learning Disabilities



Palliative and End of Life Care Standards for People with Learning Disabilities



Glossary of Abbreviations and Terms as first used, and throughout this Document

PLDs: People with Learning Disabilities - page 02

LLCs: Life Limiting Conditions - page 02

EoLC: End-of-Life-care - page 02

Prognosis: means diagnosis - page 02

Genetic or congenital abnormalities: means abnormalities that are hereditary, or present at birth - page 02

MDT: Multi-disciplinary Team - page 05

Advance Care Plan: means Future care or planning ahead - page 05

Advance Decision: It is a legal binding document, which sets out what the patient does not want to happen at the end of life stage of their lives - page 05

Advance Statement: Like the Advance decision: it sets out what the patient what the patient wants or does not want to happen at the end stage of their lives - page 05

DNACPR: Do Not Attempt Cardio-Pulmonary Resuscitation - page 05

Anticipatory Medication: 'just in case medication', which has been prescribed to be used at the End-of-life care stage - page 08

Best Interest Decision: means a decision made on behalf of someone who cannot make their own decision. It is done in accordance with Mental Capacity Act 2005. It involves the family and all professionals involved in the care of the patient/client - page 11

PRN Medication: Medication that is prescribed to be given only when needed such as pain relief - page 13

Disease Trajectory: refers to the course of an illness - page 16

Audit trail: refers to the ongoing record keeping of the assessments, re-assessments, and review of the client's care during the course of their illness until the time of their death - page 16

4

**PROBABILITIES
OF LIFE EXPECTANCY -
OR POLE**

Probabilities of Life Expectancy (POLE)

Probabilities of Life Expectancy is an End of Life Care tool developed to identify the stage of life a person is at. As their health declines, their needs will naturally increase and must be managed effectively.

Once implemented, POLE triggers specific support and promotes person-centred approaches to managing the identified needs. In turn, this increases the chance that the individual obtains quality care and comfort, as well as a dignified death.

Unlike other tools, POLE focuses on a person's changing needs, rather than just giving a timescale of life expectancy. Using this tool will help you determine the type of care required to ensure that the person's current health needs are met. We believe this is an important part of End of Life Care and helps maintain high standards of care to the very end.

As a person's health declines, it's important to identify the early signs that indicate that end of life is near.

That's because people's needs both *change* and *increase* as their health declines. And for these to be managed effectively, the Probabilities of Life Expectancy tool (POLE) should be implemented. This will improve the quality of End of Life care for the person as well as ensure that they die in a dignified and well-coordinated manner.

Meeting the needs of the individual

Focus of care should be aimed at meeting the anticipated needs of an individual rather than giving defined time scales. This is far more important than trying to work out the exact time remaining in a coded format which can sometimes lead to unintentional categorisation.

Some models identify progression to death by using a symbol. However, this can lead to the person encountering a negative experience, and as such, should be optional. If a symbol is used, then this information should be treated as a confidential document only for use by the care staff.

This guidance facilitates the choices the person has expressed regarding their end of life. It helps trigger Advance Care planning discussions, prevention of crisis admissions and enables a proactive approach to managing their needs to ensure that they "live well until they die".

Definition of End of life care

General Medical Council, UK 2010

People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is expected within a few hours or days, or those with the following:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

Guidance for professionals

People with progressive, life-limiting conditions can experience changes to the symptoms related to their conditions. It is important that such changes are identified and promptly reassessed and that the goals are re-evaluated if necessary. These decisions need to be discussed with the individual, their family and carers if present or contactable.

Depending on whether the condition can be reversed by treatment, the focus of the care team needs to be to maintain life and wellbeing. However, if it is clear that the individual's condition is not reversible, then the focus of care should be on palliation and preserving their comfort and dignity.

Five priorities for the care of the dying

There are national guidance for doctors and nurses caring for people in the last days of life. This guidance has recently changed with the withdrawal of the Liverpool Care Pathway. The "One Chance to Get It Right" document issued guidance to allow people to receive the highest quality care at the end of life.

The five priority principles of this palliative and End of Life care guidance involve:

- The possibility of end of life is recognised and communicated clearly, decisions made and regularly reviewed, and actions taken in accordance with the patient's wishes
- Sensitive communication occurs between hospice staff, the patient and those close to them
- Patients are involved in decisions about their care as much as they want to be
- The needs of families and those close to the patient are actively explored, respected and met as far as possible
- An individual plan of care which includes food and drink, symptom control and psychological, social and spiritual support is agreed, co-ordinated and delivered with compassion

Probabilities of Life Expectancy (POLE) Tool

Optimum Health

This is classed as the stage of a person's life where the person's physical, emotional, and mental health abilities are operating at their optimum best. It is also the health goals a person can realistically achieve to feel their personal best. However, even at this stage, being proactive and developing strategy can make all the difference to achieving good quality care and help the person we support 'live well till they die'. Remember that being proactive is to stay prepared.

Specific Support

It is good practice for discussions around 'Advance Care Planning'(ACP) and advance wishes take place on admission. For even at this stage, sudden death can and sometimes does occur. For example, people with epilepsy could experience sudden death even though the condition is well managed. Being well prepared not only boosts the confidence of care staff, it also reassures them that they are on the right track at such difficult times.

At this stage it is still important to do the following:

- Liaise with the GP to monitor the person's general health status and mental well being.
- Promote a holistic healthy lifestyle identified from the person-centred plans.
- Complete specific assessment tools if a person's specific need makes this necessary.

The following assessment tools, with examples attached, could help care staff achieve their goal to offer good End of Life care. Bear in mind that all these assessment tools have varying degrees of importance but together play a vital role in monitoring the health needs of a person. It should be completed by either a district nurse or the support staff.

Specific Assessment Tools

1. Medical History	2. Mental Capacity Assessment
3. Weight Chart	4. Waterlow chart
5. Bowel Chart	6. Daily Notes
7. Moving in Document	8. POLE leaflet
9. My Advance Care plan	10. What Makes my Life Complete
11. Services the client comes into contact with	12. Person Centred Plan
13. Person-Centred Plan Action Plan	14. NEWS (National Early Warning Score)
15. Healthcare Guidelines	16. Menstruation Chart
17. Healthcare Diary	18. PRN Medication Guidelines
19. Seizure Chart	20. OK Health check http://www.fairfieldpublications.co.uk/OK.htm
21. Hospital Tracking form	22. Anticipatory Medication Example
23. Bladder Record Chart	24. My Health Action Plan File To get your copy contact www.kirklees.nhs.uk/your-health/health-action-plan/
25. Nursing Care Intervention	26. Risk Assessments
27. Manual Handling Plan	

You might also put in place charts that are relevant to the person and may include:

- Assessment of nutritional status
- Modified Early Warning Score (MEWS) This monitors an individual's physical observations such as their conscious level, blood pressure, temperature, respiration rate, heart rate, and oxygen saturation levels
- Fluid balance chart
- Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) form
- Funeral plan
- Financial information

Copies of all the identified forms are located in the Appendices.

Congenital abnormalities that will affect life expectancy

There are many reasons why learning disability occurs. Impairments which cause or contribute to learning disability can happen before, during or after birth. When they occur before birth, or pre-natal, they are known as 'congenital' causes and include problems during the development of the foetus.

These relate to conditions that are present at birth as a result of either heredity or environmental influences including the health of the mother during the gestational period. For example, substance misuse during pregnancy or certain medications that the mother has taken can all have a detrimental effect on the baby from birth. Exposure to drugs, radiation and illnesses due to mutations of the genes can also manifest into a person having a learning disability such as Down's Syndrome or Fragile X Syndrome. Another possible cause of learning disability is oxygen deprivation during the birth.

Post natal causes such as illness, injury or environmental conditions, can lead to a learning disability. These include meningitis, brain injury, or children simply being deprived attention to their basic needs such as being undernourished, neglected or physically abused.

Get to know the causes

It may be useful to know the causes of someone's learning disability, as some types of learning disability are thought to be associated with particular learning characteristics. Some syndromes or impairments are associated with medical conditions such as Prader-Willi Syndrome (PWS). This is a rare genetic condition that causes a wide range of symptoms. Knowing this will enable us to help people avoid situations that may be dangerous for them, and also help us to deal with emergencies.

However, we need to remember that people value their individuality. And, as such, emphasis should be on the person and not their conditions. Like the rest of us, people with a learning disability dislike being labelled and always described in terms of their disability.

Specific Support

In addition to those listed above, the following specific support actions should also be taken:

- Liaise with all the person's specialist support network to monitor identified health needs
- Complete and review all health care plans, OK Health checks
- Allocate a named carer to coordinate the care package and liaise with the person's family
- Medication reviews
- Review ACP every 6 months and record the discussion on the review sheet
- Provide identified training for carers to meet the health needs of the person being care for. These include specialist training techniques in managing Percutaneous Endoscopic Gastronomy tube (PEG), Catheters, Tracheotomy, Stoma care, Diabetes and Epilepsy.

Life threatening conditions that respond to treatment

Not all the medical emergencies listed below are life-threatening. Some require medical attention in order to prevent significant and long-lasting effects on physical or mental health. There's a huge range of conditions that an individual may have and a large percentage of these will be undiagnosed. Certain conditions will not have a diagnosis due to medical technology not being sufficiently advanced. For example, genetic testing is one such technique that has only become available during the last ten to fifteen years.

Staff need to be vigilant and address any presenting symptoms even though a formal diagnosis is not recorded in the individual's care plans. Regular baseline assessments need to be identified for all physical observations. For example, blood pressure, temperature, oxygen saturation levels and respirations.

Injury or illness conditions include: Abdominal pain, severe appendicitis (leading to peritonitis), Crohn's disease (a severe possible obstruction or perforation of the bowel), Intestinal obstruction, Hyperthermia (heat stroke or sunstroke), Pharmacological overdose, Spreading wound infection and Suspected spinal injury.

Infections: Examples include bacterial meningitis, salmonella poisoning, kidney infections, lung infections and septicaemia (infection of the blood).

Cardiac and circulatory: Conditions include bleeding, internal bleeding, myocardial infarction (heart attack), cardiac arrhythmia (slow, fast or irregular heartbeat) and haemorrhage.

Metabolic conditions needing treatment: such as acute kidney or liver failure; malnutrition and starvation (such as extreme anorexia and bulimia); Chronic laxative abuse, and electrolyte disturbance. This last one can be severe and the client may experience dehydration, severe diarrhoea or vomiting. Chronic laxative abuse can also be included as a cause.

Neurological and neurosurgical: Examples of this may include a spinal cord injury (SCI) caused by trauma; status epilepticus (SE) (a life-threatening condition in which the brain is in a state of persistent epileptic seizure); cerebrovascular accident (stroke); brain disease or trauma to the brain; psychiatric psychosis. This is an abnormal condition or derangement which refers to an abnormal condition of the mind, and is a generic psychiatric term for a mental state.

Ophthalmological conditions: This includes glaucoma which is a term describing a group of eye disorders, where the pressure increases and can permanently damage vision in the affected eye or eyes and lead to blindness if left untreated and retinal detachment; Physical or chemical injuries of the eye can be a serious threat to vision if not treated appropriately and in a timely fashion.

Life threatening conditions that respond to treatment continued

Respiratory conditions: These include respiratory failure; pulmonary embolism (PE), a blockage of the main artery of the lung or one of its branches by a substance that has travelled from elsewhere in the body through the bloodstream; choking and asthma.

Shock: Septic shock is a medical condition resulting from severe infection and sepsis, though the microbe may be to a particular site; anaphylaxis is a serious allergic reaction that is rapid in onset; neurogenic shock is a distributive type of shock resulting in hypotension.

Urological conditions: Urinary retention, also known as ischuria, is a lack of ability to urinate.

Specific Support

- As above
- Linking with specialist services
- Review health care plans, risk assessments
- Provide adequate equipment to meet current needs and anticipated needs
- Promote effective communication and on-going support for families and carers
- Ensure involvement in all decision-making processes.

Progression of disease which no longer responds to treatment

As a person's condition deteriorates, the progression of disease will be documented in the individual's care plan and reviewed accordingly. These types of illnesses include heart failure, diabetes, liver failure, lung disease, motor neurone disease, multiple sclerosis, HIV/AIDS, kidney failure needing dialysis and certain forms of cancer.

At this stage, signs and test results will confirm such deterioration and the person will experience a reduction in their ability to independently manage their own needs. For example, they may need help with basic daily tasks such as eating, moving around, going to the toilet, bathing and getting dressed and undressed. For instance, dysphagia, the reduction in the ability to swallow, can lead to inadequate nutritional intake. At this stage, people who are terminally ill can also experience a decline in systolic blood pressure.

Specific Support

- As above
- Details need to be shared with local palliative services and out-of-hours services
- Linking closely with GPs and District Nurses
- Provide practical care assistance and promote independence by supporting self-help skills and personal care tasks which help maintain their comfort and dignity
- Encourage meaningful connections and communication with the family and carers
- Offer family guidance and support on any aspect of their relative's illness and the bereavement process and prepare them for their coming loss.
- Confirm who is the primary decision maker who will manage the information and coordinate family involvement and support
- Offer respite care such as a carer sitting with the person
- Utilise local hospice short stay services where available
- Identify any training required for care staff
- If children are involved, the information should be honest and age-appropriate. They could be encouraged to draw pictures to stimulate feelings
- Ensure any religious rituals are carried out in accordance with their ACP

Caring at the end of life

Whilst the symptoms in the final stages of life vary from person to person, there are some common ones experienced near the end of life that caregivers can provide comfort for. However, it should be remembered that experiencing any of these symptoms doesn't necessarily mean that the person's condition is deteriorating or that death is close.

If the person is likely to die within the next few days care providers need to focus on maximising their comfort and dignity, paying specific attention to meeting their holistic needs. That is to say, their physical, emotional, psychological, social and spiritual needs.

During the final hours of a person's life, most will need continuous skilled care. This can be provided in any setting, so long as the care professionals, the family and carers are prepared and supported throughout the process. The goal should be to maintain the person's comfort, and to prevent and relieve their symptoms as much as possible. Discomfort can occur in a variety of different ways. For example, pain, nausea, drowsiness, difficulty in swallowing, eating and drinking, constipation and not being in control of their bladder and bowels. When a person is experiencing multiple symptoms, it is important to establish which symptom needs to be addressed first.

Supporting loved ones

Being vigilant and carefully observing their changing needs will ensure that the person's symptoms are relieved and do not cause unnecessary suffering. This will help promote the experience of a "good death."

It is also important to be mindful of the needs of the family and carers. Practitioners need to ensure that the family members and carers know that they can spend as much time as they wish with their relative.

At this stage of the person's life, the family will possibly be experiencing anticipatory grief. The care provider should support them with a comfortable, peaceful environment, with regular contact from the care staff. This could be in the form of offering advice, or perhaps supplying refreshments for the family which can help to ease their emotional journey.

Managing the symptoms

At this point, ensuring the person's comfort is paramount. The care provider needs to ensure that any presenting symptoms are managed by introducing a specific group of drugs which may be required at the end of life. This group of drugs should be requested from the GP and the controlled drugs kept in a locked controlled drug cabinet. Naturally, they should be dispensed, administered and recorded by a qualified nurse or district nurse and witness.

These 'Anticipatory' drugs are drugs that are prescribed for use on an 'as required' basis to manage common symptoms at the end of life. In most cases they will be prescribed as a subcutaneous injection and will usually include four key drugs: an opioid for management of pain or breathlessness, an antiemetic for nausea and vomiting, an anti-secretory drug for respiratory secretions, and a sedative for restlessness and agitation.

It's a good idea to have the drugs in stock so that they are available at any time, especially if symptoms are experienced out of hours. The dispensing and administering of anticipatory drugs are, of course, at the discretion of the GP or District nurse.

Specific Support

Pain	<p>Although pain is subjective, it is very real to the individual and needs to be re assessed at regular intervals. Medication to relieve pain symptoms is required until death.</p> <p>There are different ways to administer the medication. These options should be discussed with the GP or District nurses.</p>
Drowsiness	<p>Plan visits and activities at times when the person is most alert.</p>
Becoming unresponsive	<p>Many people can still hear even though they can no longer speak; so talk to them assuming that they can hear you. It's good practice to have a familiar carer or relative with the client at all times.</p>
Confusion/disorientation and agitation	<p>Speak calmly to reassure and help re-orient the person. Gently remind them of the time, date, and people who are with them.</p> <p>Some causes of confusion can be reversible such as a urinary tract infection. These causes need to be investigated and treated.</p> <p>Sedation may help settle the person; this medication is on the anticipatory medication list. Making the environment as calm as possible is important since noise and disturbance can be stressful and make the symptoms worse.</p>
Loss of appetite, decreased need for foods and fluids	<p>Let the individual choose if and when to eat or drink. Ice chips, water, or juice are refreshing if the individual can swallow. Keep their mouth and lips moist with products such as glycerine swabs and lip balm.</p> <p>Loss of appetite is a natural part of dying.</p>

<p>Loss of bladder and bowel control</p>	<p>Keep the person clean, dry, and comfortable as much as possible. Place disposable pads on the bed beneath them and remove them when they become soiled. Urine output may decrease and become dark in colour. Checking the individual at regular intervals will ensure that their skin integrity remains intact and does not break down into a pressure ulcer.</p> <p>Reassure the person as this symptom can be distressing for them.</p>
<p>Laboured, irregular, shallow or noisy breathing</p>	<p>Breathing may be easier if the person is turned onto their side and pillows are placed beneath their head and behind their back. Sometimes, they can develop a rattle sound when breathing. A medication can be prescribed from the anticipatory medication list to dry up these secretions.</p> <p>Explaining the symptom and its cause to the family before it occurs will help them to cope. Tell them it is due to the reduced level of consciousness and it will not cause any distress to their loved one. A cool mist humidifier may also help.</p>
<p>Mouth Care</p>	<p>A dry mouth may be caused by the individual treatment, medication, disease symptoms or by the person constantly breathing through their mouth. If left untreated then this can lead to them being reluctant to eat and drink, as well as mouth ulcers and thrush. Therefore, the promotion of good oral hygiene is essential. If the person is confused or semi-conscious then fluids should not be placed in their mouth, as they could inhale it into their lungs. The mouth can be kept moist by using swabs or a small sponge.</p>
<p>Difficulty in swallowing</p>	<p>If the person can no longer tolerate fluids or diet, they should not be given them orally as this could lead to choking. It will also make them uncomfortable and distressed. The care provider should seek the advice of the Speech and Language specialist. They will offer advice on methods of rehydration and diet in an acceptable form that the person can manage.</p>

After Death

Specific Support

- As the person is dying, the care provider should support both them and their family by maintaining a calm, peaceful and homely atmosphere. Being with the family and observing the person is important. You need to communicate well with family members and tell them what is happening to their loved one in order to reassure them. Involve senior staff in this process if you don't feel confident enough to deal with it yourself.
- The verification of the person's death needs to be clarified and carried out. The care provider needs to be aware of their local policy and procedures and ensure that they are carried out correctly.
- It is important that care staff recognise the signs that death has occurred. A senior worker needs to be informed. The signs are:
 - No response
 - No pulse
 - No breathing
 - Eyes fixed
- Sacrament of The Sick procedure is carried out. This is the final act of washing the body after death and preparing it for removal by the undertaker. The care provider needs to refer to their work policies and procedures.
- After the person has died the family and care providers may want to draw comfort by taking some time to say their last goodbyes, talk or pray before proceeding to final arrangements.
- People who share the same accommodation can develop close friendships. Morally they have a right to be informed in a sensitive manner. It is important to be honest and not let them find out accidentally that their friend has died. Care staff often struggle to talk to individuals and feel they need to protect them. However, it is important to let them have the opportunity to express and show their own grief.
- Marking the person's life and death with careful thought and consideration can help their family and peers to come to terms with their loss and help them to remember the person's life. Creating a Book of Remembrance is a good way to implement or organise a remembrance day.
- After the person has died, staff may need support to talk through their experience. To avoid stress burnout staff need to look after their own well-being by taking time out, discussing their feelings with others, acknowledging their grief and loss, trying to find ways of relaxing away from work and being aware of their own limitations.

Case Studies

The following are examples of people who would be at different stages of life, as described by POLE.

OPTIMUM HEALTH

Mary is a 63 year old female with a learning disability. She has no health conditions and her vital signs are all normal. She is mobile, and is of average weight and height. If Mary was to die suddenly it would be a shock to staff and her family. Therefore it is probable she is of **optimum health** and the guidance on this section should be followed.

CONGENITAL ABNORMALITIES THAT AFFECT LIFE EXPECTANCY

James is a 22 year old male with a learning disability and Down's Syndrome but is otherwise relatively healthy. However, due to the likelihood of premature death in people with Down's Syndrome, plus complications of his condition which may affect his health in the future, it would be wise to follow the guidance on **congenital abnormalities that will affect life expectancy**.

LIFE THREATENING CONDITIONS THAT RESPONDS TO TREATMENT

Michael is a 45 year old male with a learning disability and epilepsy. Despite taking several different types of epilepsy medication every day, he still suffers seizures almost daily. There have been instances in the past 12 months where he has gone into status epilepticus. This is an epileptic seizure a person does not recover from, often needing PRN medication to bring them out of it. He has required emergency medication to stop this. In any person with epilepsy, there is also a risk of SUDEP (sudden death in epilepsy). Due to these factors which affect his everyday life, and the fact that his medication is managing his seizures as effectively as possible, it would be beneficial to follow the guidance on **life threatening conditions that responds to treatment**.

PROGRESSION OF DISEASE WHICH NO LONGER RESPONDS TO TREATMENT

Natalie is a 23 year old female with a learning disability and terminal cancer as diagnosed by her cancer specialists. Her care needs are increasing and she is slowly losing her independence. She is taking pain medication but all other treatment has been stopped by her GP. Due to these factors, it would be beneficial to follow the guidance of **progression of disease which no longer responds to treatment**.

5



COMMUNICATION

To provide your clients and their families with the right level of support, you'll need to employ effective communication skills.

Preparation

Remember to prepare the environment to ensure you're not disturbed - use a quiet room, with enough privacy.

Give the person time and don't rush. You can leave the room to give them time to absorb what you have said before returning to answer any questions.

You need to be prepared, and know the facts. The more information you have about your client's situation, the more able you are to provide accurate information and respond to any questions.

Language and approach

You should be empathetic and sensitive when discussing a client's deteriorating health issues and future plans. Be honest and factual when providing information. Your body language and facial expressions will have a big influence on how people respond to what you're saying.

Confidence comes with experience. Having the right knowledge and training will empower you to talk about End of Life Care with confidence.

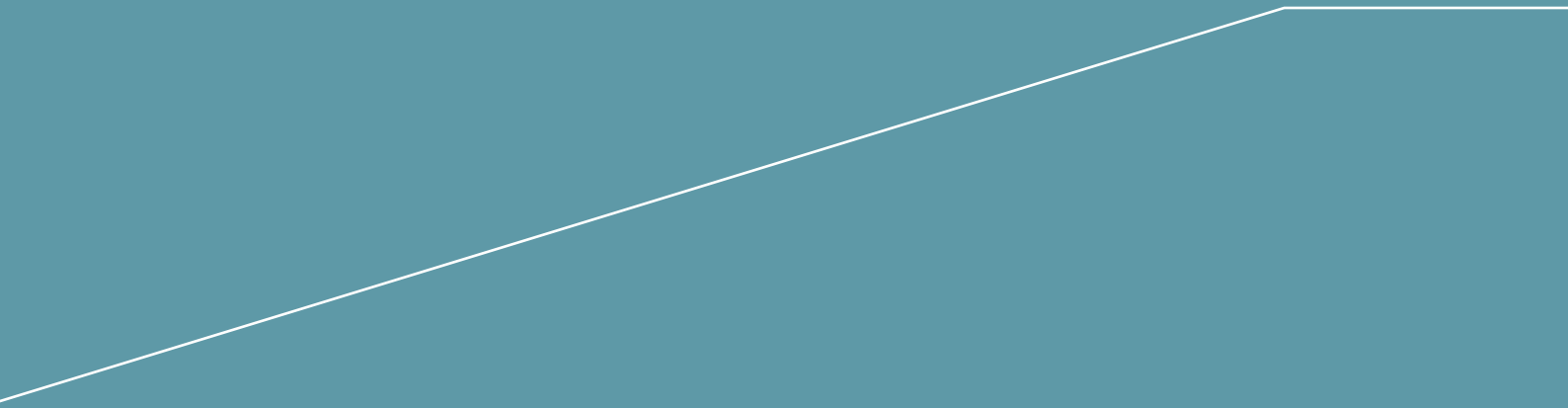
Communicating with family

It's important to get the family involved at the point of admission or diagnosis. Family members should be invited to appointments to receive first hand information, and have the opportunity to ask questions themselves.

Be approachable: discussion about End of Life issues with clients and families isn't easy, but these conversations are important. If you're approachable, you are more likely to have informal, productive, discussions with a client or their family.

Each member of a family will react differently to the situation. Understanding these dynamics will help you support the family when coming to terms with the situation and the future. Don't overload the family with too much information at once - allow time for the information to be digested and then be ready to provide more information as requested.

You should also signpost the help that's available to families, such as Marie Curie, MacMillan nurses, or the hospice family team.





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