‘Doing it my way’

PROBABILITIES OF LIFE EXPECTANCY (POLE)

A life without limits for the people we support

ST ANNE’S COMMUNITY SERVICES

Probabilities of Life Expectancy (POLE)

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.

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.

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 guidelines 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. POLEleaflet
9. My Advance Care plan	10. What Makes my Life Complete
11. Servicesthe 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. PRNMedication 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 Heath 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:

- Assessmentofnutritional status
- Modified Early Warning Score(MEWS)Thismonitorsan 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
- Funeralplan
- Financial information

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

Congenitial abnormalites that will affect life expectancy

Thereare many reasonswhy 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' causesand include problems during the development of the foetus.

Theserelate to conditions that are present at birth as a resultof either heredity or environmental influences including the health of the mother during the gestational period. Forexample, 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 illnessesdue to mutations of the genes can also manifest into a person having a learning disability such as Down'sSyndrome or Fragile X Syndrome. Another possible cause of learning disability is oxygen deprivation during the birth.

Postnatal 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'slearning disability, as some types of learning disability are thought to be associatedwith particular learning characteristics. Some syndromes or impairments are associatedwith medical conditions such as Prader-Willi Syndrome (PWS).Thisisa rare genetic condition that causesa wide range of symptoms. Knowing this will enable us to help people avoid situationsthat 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 restof 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'sspecialist support network to monitor identified health needs
- Completeand reviewall health care plans, OK Health checks
- Allocate a named carer to coordinate the care package and liaise with the person'sfamily
- Medication reviews
- Review ACPevery 6 months and record the discussion on the review sheet
- Provideidentified training for carers to meet the health needs of the person being care for. Theseinclude specialist training techniquesin managing Percutaneous Endoscopic Gastronomy tube (PEG),Catheters,Tracheotomy, Stoma care, Diabetes and Epilepsy.

Life threatening condictions 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 infaction (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 condictions that respond to treatment continued

Respiratory conditions: Theseinclude respiratory failure; pulmonary embolism (PE),a blockage of the main artery of the lung or one of its branches by a substancethat has travelled from elsewherein the body through the bloodstream;choking and asthma.

Shock:Septic shock is a medical condition resulting from severeinfection and sepsis, though the microbe may be to a particular site;anaphylaxis is a seriousallergic 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

- Asabove
- Linking with specialistservices
- Review health care plans, risk assessments
- Provideadequate equipment to meet current needs and anticipated needs
- Promoteeffectivecommunication and on-going support for families and carers
- Ensureinvolvement in all decision-making processes.

Progressionof disease which no longer respondsto treatment

As a person’scondition deteriorates,the progression of disease will be documented in the individual’s care plan and reviewed accordingly. Thesetypes of illnessesinclude heart failure, diabetes, liver failure, lung disease,motor neurone disease,multiple sclerosis,HIV/AIDS,kidneyfailure needing dialysis and certain forms of cancer.

At this stage,signs and testresultswill confirm such deterioration and the person will experience a reduction in their ability to independently manage their own needs. Forexample, they may need help with basic daily tasks such as eating, moving around, going to the toilet,bathing and getting dressed and undressed.Forinstance, 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 servicesand out-of-hoursservices
- Linking closely with GPsand District Nurses
- Providepractical care assistanceand promote independence by supporting self-help skillsand personal care taskswhich help maintain their comfort and dignity
- Encouragemeaningful connectionsand communication with the family and carers
- Offerfamily guidance and support on any aspect of their relative’sillnessand the bereavement processand 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 respitecare such as a carer sitting with the person
- Utiliselocal hospice short stay serviceswhere available
- Identify any training required for care staff
- If children are involved, the information should be honestand age-appropriate. They could be encouraged to draw pictures to stimulate feelings
- Ensureany 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	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. There are different ways to administer the medication. These options should be discussed with the GP or District nurses.
Drowsiness	Plan visits and activities at times when the person is most alert.
Becoming unresponsive	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.
Confusion/disorientation and agitation	Speak calmly to reassure and help re-orient the person. Gently remind them of the time, date, and people who are with them. Some causes of confusion can be reversible such as a urinary tract infection. These causes need to be investigated and treated. 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.
Loss of appetite, decreased need for foods and fluids	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. Loss of appetite is a natural part of dying.

Loss of bladder and bowel control	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. Reassure the person as this symptom can be distressing for them.
Laboured, irregular, shallow or noisy breathing	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. 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.
Mouth Care	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.
Difficulty in swallowing	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.

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 accidently 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.

Developed by the 'Doing it my way' End of Life care focus group: Catherine Wood, Judith Cooper, Marnie Walker, Sally Arrey, Vivian Lamptey and Joanne Seed.

ST ANNE'S
COMMUNITY SERVICES