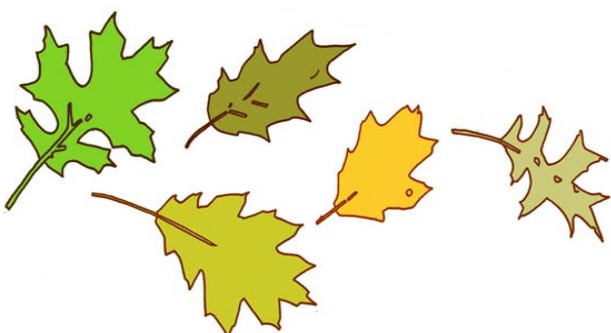


Improving End of Life Care for People with Intellectual and Developmental Disabilities

Resource Pack

Developed in partnership by
Nottinghamshire Healthcare NHS Foundation Trust and
Sherwood Forest Hospitals NHS Foundation Trust





Foreword

In recent years it has been recognised that efforts need to be made to widen access to palliative care but in spite of this it appears that inequities in provision have remained (Marie Curie, 2014, Waterman L et al, 2016, Morton-Nance S et al, 2012, Department of Health, 2008). The importance of tackling these inequities is acknowledged in the National End of Life Care Strategy (2008) and is a commitment of Nottinghamshire Healthcare. Currently, around 470,000 people die each year in England (Dixon J et al, 2015), undoubtedly a large number of these people will be from non-cancer diagnoses, they may also have co-morbidities, they may also be from 'at risk groups' such as people with intellectual and developmental disabilities, who will need and should have equitable access to high quality palliative care.

In May 2016 the Care Quality Commission (CQC) published a review into inequalities in end of life care. The review focused on end of life care for people who may be less likely to receive good care this included people with intellectual and developmental disabilities. This review provided the framework to undertake a local service evaluation which identified similarities when comparing barriers found on both a national and local level. Barriers such as; *recognition of end of life, poor communication, inequalities in accessing good care, staff awareness and non-collaborative working*. Palliative and end of life care affects all people irrespective of age, race, religion or belief. Part of Nottinghamshire Healthcare's responsibility and commitment is to ensure high quality end of life care is accessible to all. We are committed to valuing people's differences and treating everyone fairly and equally. We aim to respond to individual needs, taking into account people's disability, race, religion or belief, age, gender, gender identity, sexual orientation and spirituality - and where possible these will be included in the individual's care; this includes providing access to interpreters and hearing loops if required.

This resource pack aims to take steps to reduce the barriers faced by the patient group and support all involved in providing high quality and equitable care at end of an individual's life. The resource pack ensures:

- Delivery of high quality care for all people in all locations ensuring that those with intellectual and developmental disabilities are not disadvantaged.
- The early identification of all individuals approaching end of life.
- Initiation of discussions about preferences and wishes for end of life care.
- Inclusive Advance Care Planning that includes: assessing needs and preferences.
- Agreement of a care plan and ensuring regular review.
- Knowledge and awareness of resources and tools available to support care delivered.

This resource pack is solidly supported by the Trust as a method to support those with intellectual and developmental disabilities approaching the end of their life and their carers throughout Nottinghamshire.

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Here at Sherwood Forest Hospitals we pride ourselves in offering equality and diversity to a wide range of individuals, which is inclusive of patients with a learning disability (LD). To note intellectual and developmental disability (IDD) is the terminology increasingly used for people with a learning disability. All people regardless of their diagnosis are indeed people first, it is therefore essential that all service provisions regardless of who the providers of care are, they should all offer care and support in an individualised and person centred way.

People with an IDD have greater health needs than that of the general population (Department of Health, 2009) research demonstrates that they are more likely to die at a younger age (CIPOLD, 2013). With on average 1,200 premature deaths per a year (Mencap, 2013). Sherwood Forest Hospitals have made and continue to make improvements in the ways we deliver healthcare to our patients with an IDD.

Although discussing death and dying remains a taboo subject, with a reluctance to highlight issues or review preferred place of care and death with the individual and their relatives/carers for fear of evoking anxiety, the locally produced resources and passion for change have brought about several improvements.

These resources demonstrate how services can work together to improve end of life care, early recognition of the deteriorating patient, and advanced care planning to support discussions when needed.

All of us at Sherwood Forest Hospitals acknowledge and give thanks to the support of all involved to help us to deliver a high level of care to patients with an IDD.

Suzanne Banks

Chief Nurse

Sherwood Forest Hospitals



How to use the resource pack:

This resource pack was designed to signpost and support people caring for individuals with intellectual and developmental disabilities during end of life care. Overleaf is the intellectual and developmental disability End of Life Guideline of Provision of Care; this guidance is based on the *Nottinghamshire Guideline for care in the last year of life*. The orange section highlights what further support could be offered to a person with an intellectual and developmental disability. The pack is then colour coded in line with the Nottinghamshire Guideline and further information on each stage can be found in the following chapters. End of life care is very individualistic and the information set out in the chapters below may be needed at different stages of the guideline.

Blue Section — From diagnosis

- Recognition of ill health.
- Health Surveillance.
- Annual Health Checks and why they are important.
- Gold Standards Framework and Prognostic Indicators Guidance.
- Electronic Palliative Care Co-ordination System (EPaCCS).

Green Section — < 1 year/months

- Who may help with end of life care?
- Person centred planning at end of life.
- My End of Life Plan.
- Personal Health Files/Health Action Plans.
- Importance of communication and Assessment/Monitoring tools.
- Breaking bad news.
- Accessible Information Standard.
- Pain and Symptom Monitoring.
- The Mental Capacity Act and making decisions during end of life.
- Nottinghamshire Advance Care Plan.
- Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR).
- East Midlands Ambulance Service.

Yellow Section — Prognosis ‘a few weeks’

- Continuing Healthcare.
- Medication and Anticipatory Prescribing.

Red Section — < Than 1 week

- Last days and hours for the person.
- Five Priorities for Care.
- Things that may help.
- Last days and hours for others.

Purple Section — After death

- When a friend or family member dies.
- What to do when someone dies.
- The Learning Disability Mortality Review (LeDer) Programme.

Navy Section — Supporting the care guideline

- Telephone contacts.
- Intellectual and developmental disability directory of services.
- 4 • Accessible resources.
- Carer and professional resources.



In recent years end of life care and palliative care has received much attention and changes to practice have been and are being made, one thing has always remained *'caring for people who are close to death demands compassion, kindness and a skilled application of knowledge'* (Nottinghamshire Healthcare, 2016). In 2013 an independent review of care given to dying patients in England, 'More Care Less Pathway', was published. In response, the Leadership Alliance for Care of Dying People (LACDP) issued 'One Chance to Get it Right' (June 2014), this report outlines the approach to caring for dying people that should from now going forward be applied in England. The approach focuses on achieving '5 Priorities for Care', which should be applied regardless of the place in which someone is being cared for during the last days of their life; hospital, hospice, own or other home.

Evidence and literature shows that over the last few years it has become increasingly recognised that certain patient groups are at risk of and may encounter many forms of health inequalities and barriers to health services. In May 2016 the CQC published their review findings in 'A different ending addressing inequalities in end of life care'. This review focused on end of life care for people within the 'at risk groups', these are people who are more likely to face barriers and unequal access to healthcare, whether because of diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances; one group included was *people with intellectual and developmental disabilities*.

Learning Disability or Intellectual and Developmental Disability?

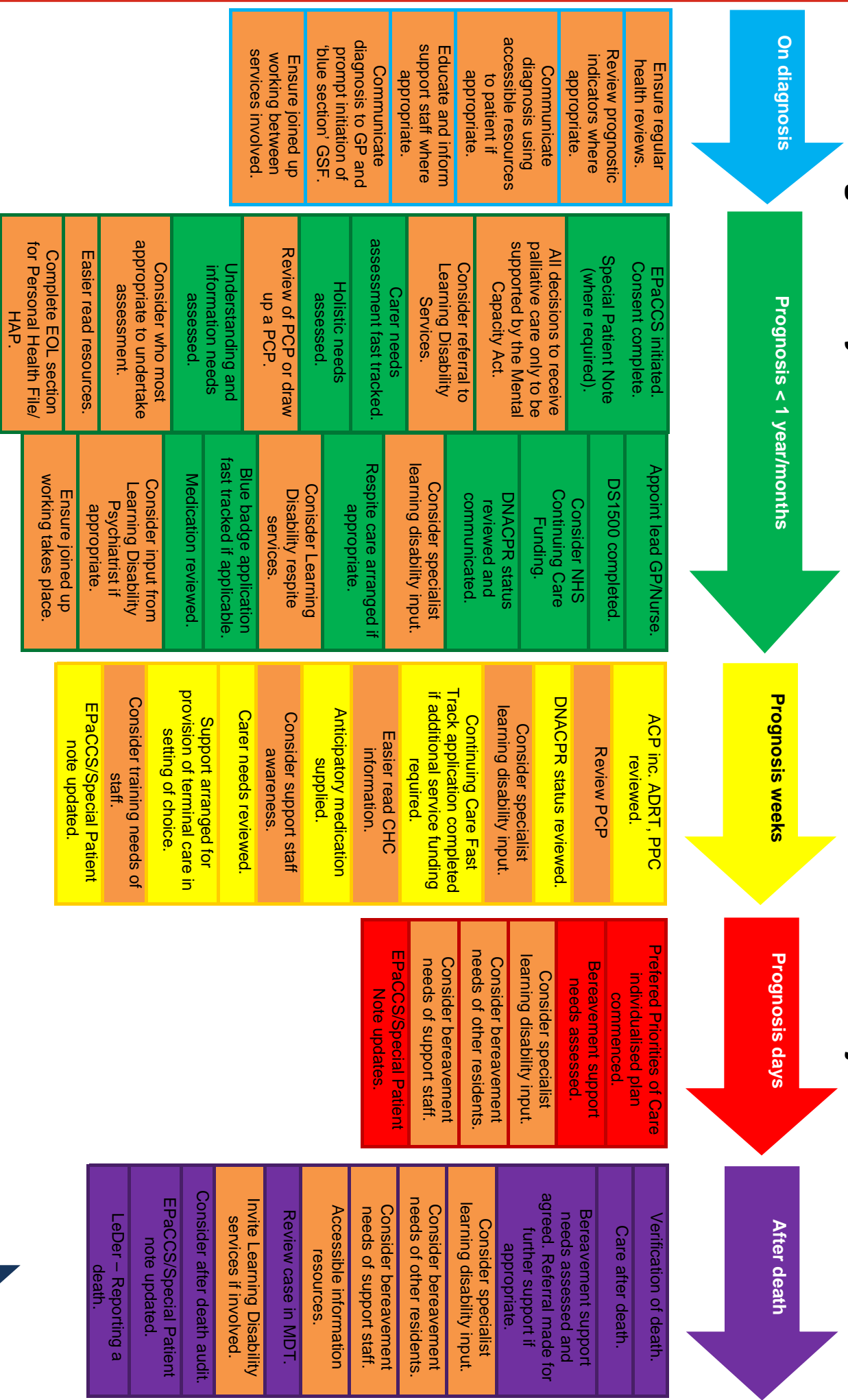
A diagnosis of learning disability (LD) requires a thorough assessment to establish that an individual meets three main criteria: a significant cognitive impairment, with an impaired social functioning, which started before the age of 18 years (Department of Health, 2001). The term Intellectual Developmental Disability (IDD) is also now currently used by academic literature and by more and more professional groups. It is for this reason that this resource pack will use this definition and it is defined as:

'...a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, which contributes to the overall level of intelligence, i.e. cognitive, language, motor and social abilities.'

(World Health Organisation, 2007).

The inequalities faced by people with intellectual and developmental disabilities often start early in life (Kerr *et al*, 2005), and are consequences of obstacles individuals face in receiving timely, appropriate and effective healthcare (Michael, 2008). One example of such evidence is that of 'The Confidential Inquiry into Premature Deaths of People with Intellectual and Developmental Disabilities' (CIPOLD, 2013). This inquiry found that these barriers are neither discriminatory nor prejudiced and can exist in the management of complex symptoms at the end of an individual's life and within palliative care.

Learning Disability End of Life Care Guideline – Reasonable Adjustments.



The following will be provided at the appropriate time according to individual patient/carer needs:

Specialist Palliative Care Condition specific palliative care Specialist psychological support Respite Care Spiritual support Self-help and support services

24 hours access to advice and co-ordination of care underpin the guideline.



From diagnosis

Recognition of ill health.

People with intellectual and developmental disabilities experience many barriers to accessing quality healthcare for serious and terminal illness, including delayed diagnosis (Public Health England, 2014) which can make recognising the end of life phase difficult (CQC, 2016). Evidence on access to effective end of life care by people with intellectual and developmental disabilities is sparse. The recent Confidential Inquiry into Premature Deaths of People with Intellectual and Developmental Disabilities showed that there were problems with their treatment or staff recognising that they were coming to the end of their lives for almost a third of people. This meant that end of life care was not co-ordinated; the person’s ability to plan and make choices affected and may lead to problems for the support for the person and their families/carers.

Both national and local evidence suggests the principal barrier to palliative care as being the lack of recognition that the individual could be in the last twelve months of their life (Gold Standards Framework, 2006). A clear thread arising is the overshadowing of the label intellectual and developmental disability onto an individual’s health status. This was reported to be felt throughout an individual’s life including the end of their life, otherwise known as ‘diagnostic overshadowing’ (Mason J and Scior K, 2004). Locally, evidence found experiences of individuals ‘hitting crises’ such as an emergency admission to hospital before any recognition was given to changes in an individual being attributed to a serious underlying physical health condition.

‘I think that’s a common theme in disabilities, that the label overshadows other physical health problems, even when an individual may be approaching the end of their life.’

Intellectual and Developmental Disability Nurse, 2017

Health Surveillance.

People with an intellectual and developmental disability do not always know when they are ill or need to see a doctor. They may not be able to tell people that they feel unwell or different (Mencap, 2016) therefore they are often reliant on those around them to notice changes or deterioration in their health. Support staff and families often notice things like change in behaviour that may indicate someone is feeling unwell, and make an appointment with the doctor.

- | | |
|---------------------------|--|
| Swellings or lumps. | Changes in toilet habits. |
| Changes in eating habits. | Generally feeling unwell. |
| Tiredness or lethargy. | Changes in behaviour. |
| Weight loss or gain. | Asking for pain relief more often than usual. |
| Personality changes. | Clothes not fitting properly due to changes in body shape. |

All those providing support, the health professionals, the families, the carers paid and unpaid all need to work together to improve early recognition of changes (National Development Team for Inclusion, 2017) and in turn earlier recognition that a person may be nearing the end of their life.



Annual Health Checks and why they are important.

There is good evidence that health checks identify unmet health needs, including life-threatening conditions. The Annual Health Check is a chance for the GP, the person with an intellectual and developmental disability and those who support them (if relevant) to review the individual's physical and mental health, it also helps to establish trust and continuity of care. It is a very important reasonable adjustment that primary care services can put in place.

Who is eligible?

People aged 14 and over who have been assessed as having an intellectual and developmental disability, profound intellectual and developmental disability, or a mild intellectual and developmental disability that may have other health needs, are entitled to a free Annual Health Check. The GP should invite all people with an intellectual and developmental disability who are eligible for an Annual Health Check each year. The GP practice should invite all people with intellectual and developmental disabilities on the health check register for an Annual Health Check. (NTDi, 2017).

In order to get a health check, people with intellectual and developmental disabilities need to be registered with a GP who provides health checks through a scheme called an Enhanced Service (ES). GPs who are part of this scheme will add those who are eligible to the health check register and these will be verified with the local Primary Care Learning Disability Liaison Nurse.

What is involved?

The Annual Health Check should be about more than metrics, such as weight and blood pressure. These things are important, but this appointment is also an opportunity for a physical examination and for the person with an intellectual and developmental disability to get to know their GP better. It enables them to share concerns and discuss how they can live a healthier lifestyle, and cope with any long-term conditions.

The Annual Health Check should include:

- A discussion about the person's lifestyle: what food they eat, whether they drink or smoke, and what exercise they do.
- A check of weight, height, blood pressure, and a check of the heart and lungs.
- A urine test.
- A check of eyes and ears.
- A check of any medicines they take.
- A check of any other conditions - for example epilepsy.
- A check of the person's mental health.
- Whether any additional checks are needed – for example a breast check.

There may also be a blood test.

The Annual Health Check should include (if appropriate) end of life care and advance care planning.



Gold Standards Framework (GSF) and Prognostic Indicator Guidance.

'GSF seeks to empower frontline health and social care providers to give the right person, the right care, in the right place, at the right time, every time, when believed to be in the last year of life.'

www.goldstandardsframework.org.uk

The aim is to improve palliative care provided by the whole primary care team by optimising continuity of care, teamwork, advance planning (including out of hours), symptom control and patient, carer and staff support.

The GSF focuses on seven key principles (sometimes referred to as the 7Cs):

- Communication
- Coordination of the person's care
- Control of symptoms
- Continuity of care
- Continued learning
- Carer support
- Care of the dying

What the Gold Standards Framework does.

The GSF helps health professionals to provide the highest possible standard of care for *all* individuals who may be in the last years of life. It does this by supporting coordinated, joined up care, so that no matter what stage of illness someone is at, or where they are being cared for, everyone involved in their care is aware of their wishes and supportive in ensuring they are met. GSF helps bring together all of the people who provide this care and assists them to ensure that the care is "cross boundary", avoiding people falling through the net.

GSF encourages health professionals to talk to their patients at the earliest and most appropriate time, about how and where they want to be cared for. Individuals nearing the end of their life deserve the best care - the 'gold standard' of care. That means high quality, reliable and consistent support.

GSF encourages health professionals to help families and carers so they can work together to avoid 'crises'. Better planning of patients' care means a last minute prescription panic or something more major can be averted.



Prognostic Indicators Guidance (PIG)

PIG is an easy to use tool to help professionals more easily and effectively identify those people who are nearing the end of their life who may need additional supportive care.

This includes people who may be within the last 12 months of life following the three main trajectories of illness;

Expected deaths – rapid predictable decline e.g. cancer.

Erratic decline e.g. organ failure.

Gradual decline e.g. frailty and dementia.

Additional contributing factors when considering prediction of likely needs include current mental health, co-morbidities and social care provision.

Three triggers that suggest that patients are nearing the end of life are:

1. The Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days'?
2. General indicators of decline - deterioration, increasing need or choice for no further active care.
3. Specific clinical indicators related to certain conditions.

Evidence suggests it is difficult to predict when someone may be approaching the last year of their life and this may be particularly so in the case of individuals with intellectual and developmental disabilities due to the likelihood of the presence of unidentified health needs (CQC, 2016). This means that individuals with intellectual and developmental disabilities are likely to be identified as approaching the end of life at a late stage; this will of course affect their ability to plan and make choices. It can also lead to problems in coordinating end of life care and providing support to the person and their family (CQC, 2016).

Identifying end of life care needs at an early stage is beneficial and can allow more time to plan appropriate support needs effectively with and for someone. If it is not clear how long this person is likely to survive, then it may be advisable to err on the side of caution and to begin end of life care planning at the earliest possible opportunity so that it can be undertaken at the emotional and cognitive pace of the individual, particularly for those with an intellectual and developmental disability.



The Intellectual and Developmental Disability Annual Health Checks via the Enhanced Service Agreement provides a comprehensive and holistic review of the patient, therefore providing an opportunity for the health professional to consider 'The Surprise Question'.

It is acknowledged that health professionals should listen more to the families and support staff of people with intellectual and developmental disabilities because they usually know most about the people they support (Public Health England, 2014) and will be able to recognise any changes that person may present.

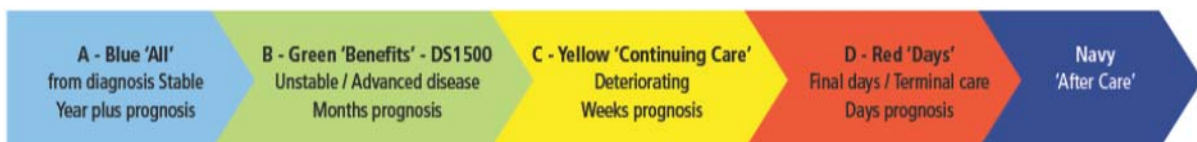
Would you recognise an individual with an intellectual and developmental disability at the end of their life?

General Indicators:

- Deterioration in the individual's usual baseline.
- Deterioration in the individual's usual ability within activities of daily living.
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity.
- General physical decline.
- Progressive weight loss.
- Repeated unplanned/crisis admissions to hospital.
- Decreasing response to treatments, decreasing reversibility.
- Blood results—Serum albumen <25g/l

Are there general indicators of decline and increasing need?

The majority of practices are noted to work well with the Gold Standards Framework within practice, but it is recommended that to reduce late recognition use of the 'blue' section within the GSF Needs Based Coding could be utilised more proactively. This section includes 'All' from diagnosis year plus prognosis, therefore inclusion of all patients with an intellectual and developmental disability with addition of a long term physical health condition could reduce vulnerable patients receiving unequitable care of the end of their life.



If a person's condition deteriorates unexpectedly, and it is thought they may die soon, i.e. within a few hours or very few days, they must be assessed by a doctor who is competent to judge whether the change is potentially reversible or the person is likely to die. If the doctor judges that the change in condition is potentially reversible, prompt action must be taken, provided that is in accordance with the person's wishes; or in their best interests, if it is established that they lack capacity to make decisions about treatment at that time.



Electronic Palliative Care Co-ordination System (EPaCCS).

The National End of Life Care Strategy recognises the importance of coordinated care. Coordination of services must exist within teams and across organisational boundaries. Methods for more effective communication between primary and secondary care have been developed in Nottinghamshire: www.epaccs.com/

When in the last year of life it is important for an individual and their loved ones, to have some difficult conversations about their wishes and preferences for their care and after death. There is a need for an organised approach to this; aimed at providing consistent best practice for patients, families and carers.

EPaCCS is a communication tool and is implemented by using the SystmOne template in an individual's electronic record. It will ensure joined up working by sharing and having access to key information about individuals, regardless of service and the time of day and night, resulting in effective cross-boundary working.

It puts the individuals' wishes at the centre of their care and helps to create an environment where clinicians can work together effortlessly. The template follows the Gold Standard Framework, with a Summary Page followed by Blue, Green, Amber, Red and After death pages, each relating to that GSF Stage.





Prognosis < 1 year/months

Who can help with end of life care?

Intellectual and Developmental Disability (LD) Specialist Nurse/Acute LD Liaison Nurses

The role of an Intellectual and Developmental Disability Nurse is to offer advice, liaison and education to staff working in the hospitals, the individual with an intellectual and developmental disability and their carers, and to liaise with community teams and support services facilitating good communication. Also part of the role is to provide education to hospital staff about the needs of patients with an intellectual and developmental disability, and advise at a strategic level to influence policies and procedures within the acute setting.

An intellectual and developmental disability nurse may support an individual at the end of their life when they access hospital care in inpatients or outpatients in these areas:

- Hospital Traffic Light Assessment.
- Helping an individual to understand what tests/treatments are taking place within the hospital.
- Helping an individual to understand their diagnosis; this may take place with other professionals.
- Liaising with hospital services to enable equal access.
- Supporting colleagues in the hospital (including end of life services) to understand the individual's intellectual and developmental disability.
- Signposting to other services that may be able to offer support.
- Supporting the individual to make decisions regarding their care in hospital.

For contact details please see the directory of services on page 50.

Primary Care Liaison Team

The Primary Care Liaison Team is a group of Intellectual and Developmental Disability Nurses that are employed by Nottinghamshire Healthcare to improve access to primary care for all individuals with an intellectual and developmental disability. The team provides support to adults with intellectual and developmental disabilities to help them understand, maintain and improve their physical health needs. This work includes advising carers and professionals on making adjustments in order to reduce health inequalities for adults with intellectual and developmental disabilities within primary care.

A Primary Care Liaison Nurse may support an individual with an intellectual and developmental disability at the end of their life in these areas:

- Health action planning including end of life section.
- Helping an individual to understand what tests/treatments are taking place within primary care.
- Helping an individual to understand their diagnosis; this may take place with other professionals.
- Liaising with primary care services to enable equal access.
- Supporting colleagues within primary care (including end of life services) to understand the individual's intellectual and developmental disability.
- Signpost to other services that may be able to offer support.
- Supporting the individual to make decisions.

For contact details please see the directory of services on page 49.



Community Intellectual and Developmental Disability Teams (CIDDT)

The teams include a wide range of health and social care specialists such as; social workers/ community care officers, welfare rights officers, transition co-ordinators, supported living co-ordinators, physiotherapists, occupational therapists, speech and language therapists, psychologists, psychiatrists and community intellectual and developmental disability nurses.

The health professionals within the team will provide information and advice to adults with learning disabilities covering a wide spectrum of health related issues. They are often best placed to provide support and assistance in the end stage of an individual's life due to the existing relationships and knowledge within the framework of the CIDDT.

At this often difficult but vital stage of an individual's life, the health focus of the team will be on supporting the individual and their carers to understand the processes involved and providing therapeutic interventions to assist with both the physical and emotional implications. They will be integral to the liaison amongst wider members of the multi-disciplinary team and to the facilitation of all required planning and implementation of the individual's care needs. The CIDDT is available as a resource to the individual and their carers, to enable informed, considered and fairer access to healthcare at a time when it is needed most.

For contact details please see the directory of services on pages 50-52.

Specialist Palliative Care

The Specialist Palliative Care (SPC) Team works exclusively in palliative care and has expertise in addressing complex patient and family/carer needs. These needs include uncontrolled pain and other symptoms, and complex psychosocial problems. It may be necessary to involve the SPC team at any stage if receiving palliative care. Holistic care is delivered using a multidisciplinary approach including medical and nursing staff, chaplaincy, social workers, physiotherapist, occupational therapist, pharmacist, clinical psychologist and complementary therapists. Care is delivered in a variety of settings such as the hospice and specialist palliative care unit, hospitals and community. Types of services available include inpatient care, outpatient clinics, day care as well as support from the Clinical Nurse Specialists within the community and hospital. Locally, the bases for these services are John Eastwood Hospice and Hayward House Macmillan Specialist Palliative Care Unit, Nottingham University Hospitals.

The SPC Team is available to give advice and support to other healthcare professionals. Education and training programmes are provided to improve the standard of general palliative care.

To contact the Specialist Palliative Care Team please ask the GP or you can call Patient Call on 01623 781891.



Palliative Care Clinical Nurse Specialists

Clinical Nurse Specialists (CNSs) are experienced nurses who are specialised in palliative care and work with the community and hospital. They are part of the Specialist Palliative Care Team, CNSs provide help and advice from the point of diagnosis onwards. The aim is to ensure that individuals and their carers have access to the best information, treatment and support. CNSs support those with cancer and other illnesses.

CNSs work with GPs, district nurses, hospital doctors and nurses, hospice staff and other health professionals involved in patients' care. CNSs can help in the following ways:

- Advise and guide individuals through the different treatments available.
- Provide advice and information on any symptoms that an individual may experience.
- Identify sources of practical help, financial benefits, written information and other helpful services available.
- Provide emotional support and time for individuals and their carers to discuss any concerns or questions you might have.
- Staff support, GPs, nurses, allied health professionals.
- Bereavement care.

CNSs can see individuals in their own home, hospital wards, outpatients department, hospice or in care homes.

CNSs may only see individuals once or it may be more often if required. This will be negotiated with the individual and is also dependant on their needs.

Specialist Nurses

There are many different types of specialist nurses, these may include; community matron, tissue viability nurse, oncology nurse, stroke nurse, respiratory nurse, colorectal nurse, diabetes nurse, epilepsy nurse, lung cancer nurse, breast care nurse and a Parkinson's nurse. Specialist nurses all have different roles but all with the objective of meeting the needs of the individual and carers.



GP

The GP is the key member in the provision of palliative care to individuals with an intellectual and developmental disability. Starting from pre-diagnosis, through the process of diagnosis, treatment, continuing illness or death and into the bereavement stages. GPs help in the following ways:

- Planning of care with the Specialist Palliative Care Team.
- Anticipation of any possible problems.
- Regular medical assessment of symptoms and advice about further management.
- Co-ordinate home care support for individuals with complex needs who wish to stay at home.
- Integrate the medical, psychological and information requirements for the individual's care.
- Assess the need for specialist help and advice for individuals and liaise with their family/carers.
- Prescribe and provide help as needed.
- Notify the out of hours team, and provide them with the information needed about the individual.
- Decide with the individual and family/carers about preferences and future care, to keep the individual in control even at the end of their life.

District Nurse

End of life care is a major part of our core service provision in the community setting. District nurse caseload holders are often named the 'key worker' for individuals who are referred from secondary care. This role is very important as it enables greater communication of important patient information by all involved with regard to diagnosis, prognosis and advance decisions etc. As a team of experienced and skilled practitioners they aim to deliver holistic care to the individual in their own home environment together with the wider specialist multi-disciplinary team i.e. GP, Palliative Care Clinical Nurse Specialist and Hospice at Home. This care could be in the form of regular support visits or more specifically treating and monitoring pain and symptom management.

It is very important that as a team they are able to establish a relationship with the individual, their family and their carers as early as possible as this can prove to be beneficial and improve the quality of care given from the beginning through to the end of an individual's journey.

To contact District Nurses please ask the GP or you can call Patient Call on 01623 781891.



Community Heart Failure Specialist Nurse

The Community Heart Failure Specialist Nurse service allows care for individuals with heart failure to be provided closer to the individual's home, working in partnership with GP practices. This facilitates the movement of individuals between primary and secondary care as their condition dictates. The aim of the service is to optimise the management of individuals with chronic heart failure by providing tailored education, review of medication, advice and support. Clinics, visits and telephone contact from a heart failure nurse specialist will be determined by individual need. This will reduce unnecessary admissions and readmissions to hospital as well as improve the quality of life for individuals. The service enables GPs, as well as cardiologists, to refer patients who are newly diagnosed or present with worsening symptoms of left ventricular dysfunction confirmed by an Echocardiogram. The service is also available to provide education and support to primary care staff and to provide palliative care support for heart failure patients and their carers. In the case of individuals with intellectual and developmental disabilities, who have heart failure, being referred to the service they would require support and advice from the intellectual and developmental disability health facilitators and equally can provide advice to them from a heart failure perspective.

Community Matron

The Community Matron is an experienced nurse who provides nursing care and case management to people with single or multiple complex long term conditions. Advanced clinical skills allow the Community Matron to identify early warning signs, investigate and diagnose exacerbations of illness, and arrange for treatment to be implemented. A proactive service is provided in order to communicate and work collaboratively with all health professionals, carers, relatives and social services.

All patients with an intellectual and developmental disability and a long-term condition e.g. chronic obstructive pulmonary disease, coronary heart disease, diabetes who are referred to the service will be supported and treated without discrimination. Despite any communication challenges we may encounter, we will endeavour to liaise with their family and carers accordingly. We can provide education of the natural progression of conditions and can establish individualised care plans to empower carers and families to identify any changes in the health status, seeking professional advice where appropriate ensuring the right care at the right place and at the right time.

These are just some of the professionals that may help support an individual at end of life; we acknowledge that individuals have different needs therefore requiring alternative avenues of support. Please ask the professionals involved in the individual's care for further information on services.



Person centred planning at end of life.

Making choices and decisions is important to all people during 'end of life' including those with an intellectual and developmental disability. Discussing and planning a person's wants and wishes is important throughout their life. This is often forgotten once a person is on the end of life care pathway but is vital to the person having a quality of life during this time.

What is person centred planning?

Person centred means doing things the way the person wants things to be done. Person centred planning is a way of helping people to think about what they want now and in the future. It is about supporting people to plan their life and work towards their goals. In person centred planning the person is in charge but a group of people may support the person to plan parts of their life.

Person centred planning might be able to:

- *Help the person make choices about things in their life.*
- *Help the person tell other people about what is important to them.*

What do person centred plans look like?

Person centred plans look different for every person, but they should **always** be **colourful**, **creative** and **fun**. Person centred planning does **not** look like a care plan. There are different types of person centred planning.

Person centred plans: the tools

There are a number of tools for person centred planning. They all follow the below principles:

- The person is at the centre.
- Family and friends are partners in planning.
- The plan focuses on gifts and capacities and looks to the future.
- Planning builds a shared commitment to action.
- Planning is an ongoing process.

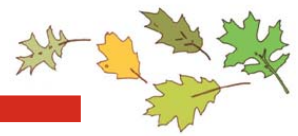
Which tool is used depends upon the person and their life, see the following link for further information.

www.nottscountypb.org/Libraries/Local/734/Docs/PCP/pcp%20tools.doc

Person centred thinking (see page 48)

Person centred thinking is a way of working, there are a number of tools which people who provide support can use to help them work in a more person centred way.

- How to sort what is important **to** a person from what is important **for** them.
- How to address issues of health, safety and risk whilst supporting choice.
- How to identify what the core responsibilities are for those who provide paid support.

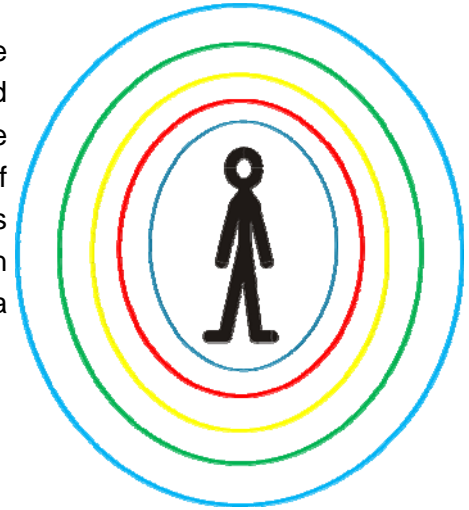


- How to consider what makes sense and what does not make sense about a person's life.
- How to ensure effective support by matching characteristics of support staff to the person's needs.

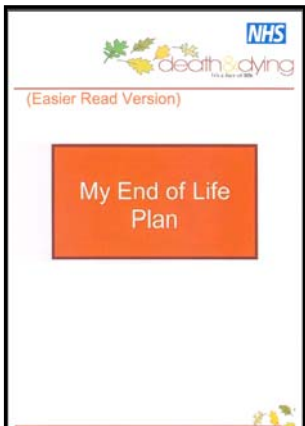
The person centred thinking tools are fundamental to all other person centred approaches.

Circle of support

A **circle of support** is describing a number of people who provide support and/or friendship to a person with an intellectual and developmental disability. Everyone within the circle should know the person well and care about what happens to them. Having a circle of support is a good way of helping the individual to achieve the goals outlined in their person centred plan. It may also help to support with any changes they may need to make in their life. It may be a good idea that regular circle of support meetings take place.



My End of Life Plan.



This plan belongs to the person and outlines their wishes and choices that they have made for when they die. The plan can be used as a starting point to begin discussions with an individual regarding what will happen when they die; things such as what type of funeral they would like, who they would like to be informed and what to do with their possessions.

Some individuals may only want to discuss some aspects of the plan which is fine and for others we may have to discuss the plan with a few important people in their lives and complete it in their best interests. A person does not have to be on the 'end of life' pathway for this plan to be completed; anyone can plan for the future.

What should happen?

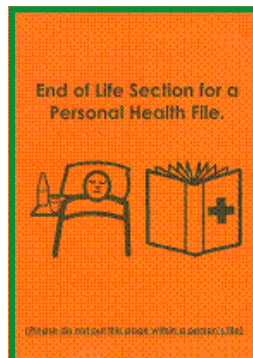
- It's important that people have a choice of what will happen when they die.
- This plan is a record of their choices; if their choices change their plan will be updated.
- People that support the individual should be aware of their plan. The plan should be kept in a safe place.
- The plan should be checked during any routine reviews that the individual has.
- Resources to help you start discussing death and dying can be loaned via an information plan.

A copy can be downloaded from www.nottscountypb.org



Personal Health Files/Health Action Plans.

The Government says in 'Valuing People Now' (2008) that every individual with an intellectual and developmental disability should be offered a health action plan and family doctors should know all their patients who have an intellectual and developmental disability. Personal health files and health action plans are a good way to help people look after their health needs. They help people to keep all their health information in one place. Successful communication during an individual's end of life is vital to ensuring a high quality of care, and using a personal health file can play an important role when used effectively. To ensure all essential information is included, a section to be used during an individual's end of life and added into a personal health file is available. To obtain a copy please contact your intellectual and developmental disability health facilitator.



For contact details please see the directory of services page 49.

Importance of Communication and Assessment/Monitoring Tools.

Good communication

Effective communication is of key importance at the end of life. Many people with intellectual and developmental disabilities have significant difficulties in communication; with both expressing themselves and understanding what others say. Strategies to support optimum communication at this time are crucial.

Good practice

- Ensure someone is always accompanied to appointments by someone who knows them and their communication needs well.
- Try and avoid multiple appointments if possible — one stop shop is best.
- Make sure glasses and hearing aids are worn.
- Prepare someone before a meeting or doctor's visit so they know what is going to happen and what to expect.
- If possible have a preliminary discussion with carers/speech and language therapist before an important meeting so that relevant resources can be prepared in advance.
- Remember that anxiety, fatigue, recent epileptic seizures, medication and the environment can all have an effect on a person's communication.



Helping someone's understanding

- Ensure you have the individual's attention before talking to them — a quiet environment helps.
- Wherever possible **show** someone something as well as telling them.
- Back up speech with non-verbal communication — signs, gestures and facial expression.
- Support speech and written information with 'visuals' such as photographs, pictures and symbols.
- If an individual has a communication book — please use it.
- Do not speak too quickly.
- Use short, simple sentences.
- Avoid complex or abstract vocabulary and explain new information words.
- Check an individual understands by asking them to tell you what you have said — NOT by simply asking 'Do you understand?'
- Allow plenty of time for an individual to process information.
- Simple summaries of discussions and information should be given to the person. They can then go through this several times with someone — to ensure it has been properly understood.
- In the late stages of an illness **touch** can be very important — and reassures someone that they are not alone.

Helping someone to express themselves

- Allow plenty of time.
- Reduce background noise.
- Sit face to face with the individual and in a good light.
- Be alert to attempts at non-verbal communication, e.g. eye contact and facial expression.
- Be aware that being able to speak does not necessarily mean an individual has good understanding.
- If you don't understand what someone says, ask them to say it again more slowly or to try and say it another way.
- If an individual has a communication book or communication aid, please encourage them to use it.
- Similarly, if an individual uses signs ensure there is someone available to sign with them.
- If important pictures/symbols that help to express end of life wishes are needed, contact the Speech and Language Therapy service for support.
- Involve a 'communication partner' who knows the individual well and can help 'mend' any communication breakdowns that may occur.



Assessment and monitoring tools— Hospital Traffic Light Assessment tool

Within Nottinghamshire County and Nottingham City, the 'Hospital Traffic Light Assessment' (HTLA) is being introduced into the community for individuals with an intellectual and developmental disability to bring into hospital with them; the document is based upon Gloucestershire NHS Trust HTLA. The HTLA provides staff with specific person centred information to help support the individual through their time in hospital.



Following the colours of a traffic light, the **Red** section details essential information; including personal details, how to approach the individual to carry out medical interventions etc. The Nottinghamshire document has been amended to include information on if an Advanced Decision or Directive has been made for future care. The **Amber** section highlights the areas in which an individual would need support within hospital; including specific and concise information which is needed to help staff support the individual with an intellectual and developmental disability effectively. The **Green** section details the individual's likes/dislikes and what is important to them; this could detail anything from food preference, routines, hobbies or how people like to be talked to.

The HTLA is used as a baseline for how an individual is when well, although in relation to end of life care, the HTLA provides information of what is important to the individual overall in their life and what is important for them to be supported with in relation to hospital care. As also described previously, the HTLA documents must if an individual has made an Advance Directive on any future care; this would help in end of life situations if an individual is unable to communicate wishes and preferences that these can be honoured. This also relates to the section where it documents if a lasting power of attorney has been appointed; this person would legally act on the person with an intellectual and developmental disability's behalf if the person loses capacity at the end of their life. Hospital staff would be aware that the person highlighted as a lasting power of attorney should be consulted on decisions.

An example of how the HTLA was used in end of life care:

A lady who was on the end of life pathway had been given information on her diagnosis with a family member, and provided the information in a way which she understood. This enabled her to make an informed decision on how and where she would like to receive end of life care. The document also highlighted that she had a cuddly bear, and it was important to the lady to have the bear with her in situations where she was afraid or anxious (i.e. radiotherapy treatment), which comforted her immensely. The lady was also very reticent to 'bother' staff if she felt in pain, so staff became aware that they needed to directly ask the patient if she felt in pain, or regularly offer pain relief.

DisDAT

This tool is used to identify and monitor distress in an individual with an intellectual and developmental disability. The tool looks at describing a person's usual self in communication, appearance, vocal signs and postural observations. This enables any signs of distress to be monitored and acted upon in a timely matter. The tool was developed by Lynn Gibson, Dorothy Matthews and Dr Claud Regnard.

For the latest version of DisDAT see www.mencap.org.uk



My Pain Profile

“Imagine feeling severe pain and not understanding what is happening, nor even being able to ask for help and information. That is frequently the case for people with profound intellectual and developmental disabilities who cannot communicate verbally. Yet when distress and anxiety alter their demeanour, it is often dismissed as ‘challenging behaviour’ until the illness causing the pain reveals itself in some other way.” (R. Astor, 2001)

My Pain Profile aims to support the identification of pain in individuals that may not be able to communicate verbally when pain is being experienced.

The My Pain Profile can be completed at any time by an individual or by a person that knows them well. This can then be used with the Assessment of Pain insert to help identify if an individual may be experiencing pain and relief may then be sought.

The My Pain Profile can be used in a variety of settings to help manage a person’s pain within the home environment or inform health professionals caring for the individual during a hospital admission.



The aim of the tool is for people caring for and/or supporting the individual to stop for a moment and think about non-verbal signs of pain.

This can be downloaded from: www.nottscounty.pb.org/

My Symptoms

There may be times when a person with an intellectual and developmental disability may be unable to tell us when they are in pain or feeling unwell. This chart will enable those caring for the person to clearly document and be aware of non verbal behaviours or signs indicating pain or discomfort. As someone that knows them well, family/carers may be aware of behaviours or signs that this is happening to them. By noting these on the chart it will help the nurses to ensure they are comfortable and symptoms relieved either in hospital or in the community.

This information should be kept close to the person for all members of the team to use.

Copies of the chart can be sourced by professionals from either Nottinghamshire Healthcare on Connect or Sherwood Forest Hospitals’ intranet.

My symptoms

Nottinghamshire Healthcare
NHS Foundation Trust

There may be times when your relative/friend is unable to tell us when they are in pain or feeling unwell. As someone that knows them well you may be aware of behaviours or signs that this is happening to them. By noting these below it will help the nurses to ensure they are comfortable and symptoms relieved. Ward staff will also note these below once we have got to know the non-verbal communication of your relative/friend.

This information will be kept close to your relatives/friends, used for all members of the team to use.

Address/graph

My behaviour: (e.g. pulling at bedding, curled up, rubbing brow)	The symptom I may have is: (e.g. pain, feeling sick, cramps)

positive about integrative healthcare

Originally developed by:
Suzanne Appleby
Derry Teaching Hospitals NHS Foundation Trust, 2016.



Breaking bad news.

Being told that a person has a life limiting condition is a difficult process for all involved. The East Midlands Cancer Network and Palliative Care Group have produced guidelines for healthcare professionals to help them break bad news to patients, families and carers. These guidelines include an 11 step process as a framework to follow, this section outlines additional factors that may need considering when delivering bad news to an individual with an intellectual and developmental disability.

'The basic model within these guidelines can be used for patients with intellectual and developmental disabilities but additional factors need to be taken into account. The patient's nominated key worker may be of particular value supporting the patient. There are a number of resources which can help.' (Breaking Bad News Guidance, East Midlands Cancer Network, 2010)

Outlined below are the 11 steps to breaking bad news which are usually followed by the health professional(s) delivering the diagnosis but they made also need support understanding this from a person that knows them well.

11 steps to breaking bad news

Step one — preparation and scene setting

- *Know all the relevant facts*—does the person receive input from an intellectual and developmental disability professional? Is it beneficial to make contact prior to delivering the news? How does the person communicate and what is their level of understanding? Will accessible resources be needed to support the verbal information? Consideration should be given to who has the necessary skills to be the deliverer of the news; it may be the doctor, but someone familiar to the individual with the doctor's support.
- *Who to be present* — if the individual is assessed as lacking capacity, is it in their best interests to be present? As some may find this environment distressing. Does the individual have an advocate? Wherever possible, allow the individual to decide who will support them through this process.
- *Set time aside* — allow more time for the appointment than usually allocated, as the individual may need extra time in processing and understanding the information given.
- *Ensure privacy and set the scene* — where should the news be delivered, would an alternative place to the health setting be more appropriate? Consider any sensory impairment.
- *Introduction* — consider your appearance; some people with an intellectual and developmental disability find a health uniform threatening and scary. Explain your job role using language but don't patronise.



Step two — what does the patient know?

- When checking an individual's understanding of what is happening to them, ensure again that the information is given at a level the person understands i.e. short, simple language, photographs and pictures, objects of reference. Consider seeking advice from an intellectual and developmental disability professional.
- Additional information may need to be sought from others involved in their care.

Step three — is more information wanted at that time?

- Observe for non-verbal cues that the individual is declining further information at this stage. The person(s) supporting the individual may be best placed to advise if this is the case.

Step four — giving a warning shot

- Again, ensure this is given in a way the individual will understand.

Step five – allow the patient to decline information at this time

- Do not assume that an individual with an intellectual and developmental disability will not require further information due to their level of understanding.

Step six— explain (if requested)

- Use alternative forms of information if needed, seek advice from an intellectual and developmental disability professional if necessary.

Step seven – elicit and listen to concerns

Step eight – encourage ventilation of feeling

Step nine – summary and plan

- Does the individual require a plan in an easier read or accessible format? Providing a written summary will allow the individual to review at their own pace the information given. The plan should be person centred and be a holistic view of the individual.
- A section covering end of life is available for the individual's personal health file which may be introduced at this stage to document all relevant information.

Step Ten – offer availability and support

- When offering further appointments write down the dates and times for the individual. If the individual lives independently, contacting the individual by telephone the day before is often beneficial.

Step eleven – communicate with the team

- Ensure communication is made with any professionals involved from intellectual and developmental disability services.
- Any letters sent to the individual need to be written in simple language but still retain all relevant facts.



Accessible Information Standard.

The implementation of the Accessible Information Standards in 2016 (NHS England) enforces all organisations that provide NHS or adult social care to follow this standard by law. This standard aims to ensure that services must ask about an individual's communication needs and find out how best to meet them, professionals must then record people's needs in a set way. Once this information is known then health and social care service provisions must highlight a person's needs and clearly explain how these needs can be met. The information on a person's communication needs must then be shared where consent/permission is given or in a person's best interests where they lack capacity to consent for this decision. Finally, health and social care services must make sure that people get information in an accessible way and offer additional support if and when a person needs it.

Information Plan

Information plans offer patients and their carers timely and relevant information at the point that they need it most. Information can be about anything from their condition to leisure activities, benefits advice and support groups to name but a few. Information prescriptions are a way of ensuring information needed is provided to patients and carers quickly and easily.

What's inside an end of life information plan?

Examples of information that may be included:

- Their condition and what may happen in the future.
- What is palliative care?
- Help and support available.
- Voluntary support and community groups.
- Ways to help them.
- Benefits, legal and financial advice.
- Medication and treatment.

Information plans for a person with an intellectual and developmental disability

An information plan is available in an 'easier' read format for individuals with intellectual and developmental disabilities. This plan of information will then be provided in a more accessible format to aim to meet individual needs.

Information can also be provided in other formats for family/carers.

Further information can be obtained from Nottinghamshire Healthcare's Connect site.



Pain and Symptom Monitoring.

As a person's condition changes it is natural for them to experience some symptoms, including pain, relating to their condition. Below are a few of the more common symptoms present during end of life, although these will be dependent upon an individual's condition and prognosis. It is important to document and monitor any symptoms experienced and discuss with the healthcare professionals involved how they can be minimised and managed.

Breathlessness

At the end of life some individuals may feel breathless; this can be very frightening and unsettling, not only for the individual themselves but also for the carers supporting them.

These feelings of anxiety can actually then make the breathlessness worse so people caring for the person need to be aware of this.

Things to consider:

- Try to reassure the individual and explain to them in a way that they understand what is happening, give some one to one support until the symptoms ease.
- Look at the position the individual is seated or lying in; does the individual need another pillow to provide more support, does this ease the problem?
- Is the individual hot? Will opening a window or having a fan in place help?
- Can the individual be talked through relaxation techniques to help with their breathing?

Tiredness and lack of energy

When individuals become more ill they gradually become less able to do the things they previously did and have less energy.

Things to consider:

- Plan so that the individual has time to rest during the day but also has time to do things they enjoy. Consider creating an accessible timetable.
- Help the individual to be realistic in planning their days/weeks after their diagnosis; they may have been active on a daily basis however now the individual may need a rest day in between.
- Explain to friends and family that the individual may not have the energy to do some of the things they enjoyed previously.



- Use imagination and be creative in supporting the individual to maintain social relationships when fatigue prevents them from going out.
- Try to maintain the individual's usual sleep pattern during the night and wake the same time each day.
- Encourage the individual to participate in some form of exercise.
- Try to keep a steady temperature in the individual's room.
- Encourage the individual to have supper so a 'growling tummy' won't wake them.

Constipation

Individuals who do not move around as much and are not eating and drinking as usual may get constipated. Many medicines taken during advanced illness can also cause constipation as a side effect; this applies especially to pain relieving drugs. This symptom can be a major problem for individuals at the end of their life and is often not identified until the individual complains of pain/discomfort; this can cause much anguish and frustration for individuals and their carers.

Things to consider:

- Keep a food diary to monitor the individual's fibre intake; a health professional can offer further advice.
- Try to encourage fluids.
- Maintain gentle exercise when possible.
- Tell the individual's GP or nurse as the problem may be due to medications the individual is currently taking. Do not stop or alter any medications without the advice of a health professional.

Loss of appetite

As the illness progresses some individuals may lose their appetite and weight. This may be because of the disease or the psychological state of the individual, such as fear of vomiting, depression, anxiety or an aversion to the quantity of food given to them.

As individuals become more ill their metabolism slows down. The body cannot digest food as well therefore it is very important not to insist that people eat.

Many carers feel that food is a very important part of life and worry when food is refused believing that the individual is 'starving to death' and that they are being neglectful by not getting the person to eat. It is important for carers to understand that at the end of their life people do not have the same nutritional needs, food cannot 'build up their strength' and in fact this may be one of the few aspects of life that the individual can retain some control over.

Things to consider:

- Have a list of the individual's 'favourite' foods and encourage these.
- Keep a food diary to monitor the individual's intake.
- Encourage little and often and ensure that foods are calorie rich such as adding cheese, using full fat milk and yoghurts.



- Try changing the plate size so that the individual does not feel overwhelmed by the amount of food.
- Make the food look nice using foods bright in colour and flavoursome.
- Have snacks available for when the individual wants something straight away.
- Contact the individual's health professional to discuss use of 'build up supplements'.
- Consider the environment, is it relaxing, familiar and comfortable for the individual to eat in?

Feeling sick and vomiting

This can be due to the illness itself or the medication that someone is taking. Individuals who are ill often say that this symptom of feeling sick is more distressing than actually vomiting, or than some types of pain and therefore it is very important that the people caring for these individuals know this.

Things to consider:

- Encourage the individual to avoid fatty, greasy and fried foods.
- Some individuals find eating drier foods such as crackers or toast in a morning helpful.
- Try having drinks in-between meals rather than with food; some individuals find fizzy drinks to be a remedy.
- There may be other physical reasons for the symptom, seek further advice from a health professional.
- Encourage little and often rather than a big meal.
- Check with the doctor/nurse to see if the individual has medication to help with the symptom or their current dose may need to be increased by the health professional.

Mouth problems

Individuals can sometimes develop very sore mouths at the end of their life; this can be a very distressing symptom for some people and may require treatment interventions and close monitoring. This symptom may be caused by the side effects of some medicines (dry mouth can be a common side effect).

Palliative treatments such as chemotherapy and radiotherapy can also cause sore mouths.

Things to consider:

- Maintain regular mouth care, a smaller and softer tooth brush may need purchasing if the mouth is sore, good lip care is needed and the individual may need Vaseline or lip balm applying regularly.
- Try to cleanse the mouth with unsweetened pineapple juice.
- Encourage the individual to avoid foods which may be dry or difficult to manage when having a sore mouth and encourage plenty of sauces and gravy with meals.
- Is the individual on medication to help manage their saliva, if so speak to the health professional about the dry mouth as this may need reviewing.
- Try to encourage the individual to drink through a straw.



Eating and drinking

As individuals get older their eating and drinking habits change and this is especially the case for people with life limiting, life threatening illnesses and those reaching the later stages of their life.

As activity levels diminish it is normal to eat and drink less but it can be difficult for carers to decide how much food and drink is appropriate or if there are any specific reasons why someone is having difficulties and how to support them.

Things to consider:

- Does the individual require assessing by a dietician for supplements?
- Does the individual require assessment by a speech and language therapist to assess their swallow?
- Might the individual need adapted cutlery, seating or environment to help manage their difficulty?

Mobility

As individuals get older their ability to move around can change; they can get slower, be less flexible and can fall over more often with no apparent cause. This is especially the case for people with life limiting, life threatening illnesses and those reaching the later stages of their life.

It is normal for activity levels to diminish but it can be difficult for carers to decide whether this is appropriate or if there are any specific reasons why someone is having difficulties and how to support them.

Things to consider:

- Think about a referral to physiotherapy. Is there an exercise programme to help the individual maintain their mobility?
- Does the individual require specialist equipment now to maintain their mobility?
- Is the individual tired and lethargic which results in problems with their mobility?
- Is the individual in pain or discomfort, resulting in an unwillingness to mobilise?

Complementary therapies

Many people with an intellectual and developmental disability enjoy complementary therapies during their everyday life. These could be particularly helpful to an individual during the end of their life to improve relaxation and comfort.

Some examples of different forms of therapy are:

Aromatherapy – The use of natural oils with therapeutic properties.

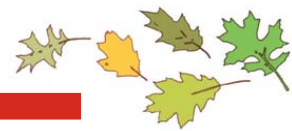
Massage – To help individuals relax, soothe muscle pain and general comfort from contact.

Reflexology – Specialised foot or hand massage.

Acupuncture – Acupuncture needles inserted to different parts of the body to affect the flow of energy.

Art therapy – To help people express themselves through art.

Music therapy – To help people express themselves through music.



The Mental Capacity Act and making decisions during end of life.

The Mental Capacity Act 2005 provides a framework for decision making on behalf of those over the age of 16 who lack capacity to make a decision about a health or social care issue.

What is capacity?

Broadly speaking, capacity is the ability to understand the issue, retain and process the information about it so as to come to a choice, and communicate the decision about the issue in any way.

Planning for future incapacity?

An individual can make decisions now, while they have capacity, for a time when they may lack capacity in the future. This ability to plan for future incapacity is a right for all people including those who have an intellectual and developmental disability. The Mental Capacity Act clarifies the rules relating to planning for future incapacity.

What's in a name?

There may be some confusion about terminology. Can someone set up an 'Advance Directive', a 'living will' or an 'advance statement'? An advance statement in Scotland has a different meaning and legal status to an advance statement made south of the border. 'Advance Directive' is old legal terminology which has fallen out of use – except perhaps (as with the term 'living will') – with the public.

The Mental Health Act Code of Practice (Chapter 17) refers to advance decisions and to advance statements. The Mental Capacity Act Code of Practice (Chapter 9) refers to advance decisions. Chapter 5 of the Mental Capacity Act Code of Practice refers to statements of wishes and feelings in the context of making a decision in a person's best interests. Professionals, carers and anyone advising on the subject should be clear about the difference between advance statements and advance decisions to refuse treatment and be able to help the person with an intellectual and developmental disability to understand the difference.

What is an advance statement?

If a person is over 16, he/she can express their wishes relating to future care, and relating to treatment that they would prefer (such as what medication or care works well for them in a crisis), who they would want (or not want) to be contacted in the event of admission to hospital – in fact anything that is important to them that they would want carers to take into account if they were unable to tell them. The list could be very short or very comprehensive and will, of course, differ from person to person. This is an advance statement. This information is not legally binding on doctors or other professionals but the law requires the bits of it that are relevant to a decision about the person who lacks capacity to be taken into account. This must be evidenced in the decision maker's notes.



What is an advance decision to refuse treatment?

In amongst their expression of wishes there may be a desire not to have a particular medical treatment in the future. Because this is a desire not to have a medical treatment, it is an advance decision to refuse treatment. The person has to be over 18 to do this. 'Refuse' is a key word – a person cannot demand treatment in an advance decision (in fact they cannot demand treatment at all). 'Treatment' is also a key word. It is about medical treatment - not any other aspect of care.

An advance decision could be made either verbally or in writing in most circumstances. So, the person could express their wishes about treatment refusal verbally, but there are disadvantages to that as it may be difficult to prove who said what and when. It is advisable to write the requirements down and be very clear about exactly what treatment is being refused and the circumstances in which it would be refused. The person should discuss their requirements with the doctor responsible for their treatment, although they do not have to get their agreement or permission. An advance decision to refuse treatment that is clearly expressed and is applicable to the treatment in question is likely to be legally binding on doctors.

It is important to recognise that if the person wishes to make an advance decision to refuse life sustaining treatment - for example terminal cancer treatment - the law requires specific formalities to be undertaken. The advance decision must be in writing, signed, witnessed and signed by the witness, and contain wording to say that the refusal is to apply 'even if life is at risk'. Note that the requirements are for the advance decision to be signed – not necessarily by the person. If the person with an intellectual and developmental disability is unable to write but is able to make their requirements known he/she can get someone to sign on their behalf. It must be clear that the person is signing on the other person's behalf - and under their instruction - and this must be witnessed.

What is Lasting Power of Attorney?

If a person should become unable to make decisions for themselves in the future, someone will need to make decisions for them. Who does this will depend on the situation. Generally, professionals will make decisions about a person's health and social care, and their family or carers will decide on day-to-day matters. If they wish, they can officially appoint someone they trust to make decisions for them. This is called making a lasting power of attorney (LPA). This enables them to give another person the right to make decisions about their care and welfare. They can also appoint an attorney to decide on financial and property matters. There are special rules about appointing an LPA.

To find out more, read GOV.UK's advice on making a lasting power of attorney:

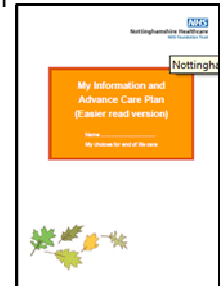
www.gov.uk/power-of-attorney



Nottinghamshire Advance Care Plan (Easier read)

This is a form of advance care planning that can give the individual the opportunity to think about, discuss and document their wishes, and lets people supporting them know about what they want. This document is used across all end of life care services and an easier read version has been developed for people with intellectual and developmental disabilities.

A copy of this document can be downloaded from www.nottscountyhb.org.uk

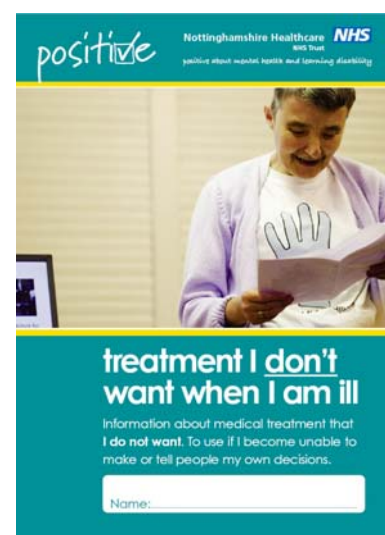
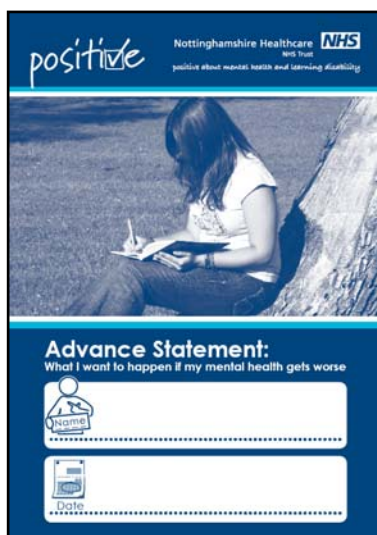


What about patients detained under the Mental Health Act?

If the person is a detained (sectioned) patient it is important to know that the law currently allows refusal of treatment for a mental health condition to be overridden if doctors consider that the treatment that the person is refusing is the only treatment that will work in their case. It does not mean that their refusal will automatically be overridden, and doctors must clearly demonstrate that it is medically necessary to override their wishes to refuse the treatment. A person can still refuse treatment for a physical condition that is unrelated to their mental health condition - such as cancer.

How can someone get help to set out their wishes and requirements?

Nottinghamshire Healthcare has produced booklets in different styles and they are available for anyone with an intellectual and developmental disability if they wish to use them, although they are under no obligation to do so. The person may want to ask their clinical team about the availability of these booklets. In addition, an advocacy service may be able to help.





Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) Allow Natural Death (AND).

What is CPR?

Cardiopulmonary arrest is when an individual's heart stops beating and their breathing stops. It is sometimes possible to restart the heart and breathing with emergency treatments called cardiopulmonary resuscitation (CPR).

Even if CPR does work, this is an invasive procedure and the individual may sustain an injury. They may also spend a lot of time in hospital, which can be upsetting for those involved. Some people never return to the level of physical or mental health they enjoyed before. Some may have brain damage or go into a coma.

Who would decide?

An individual can choose not to have CPR and allow natural death. If this is their choice then an Advance Decision to Refuse Treatment (ADRT) can be completed. Otherwise, a doctor or healthcare professional caring for the individual will make a clinical judgement about whether to attempt CPR based on how likely it is to succeed.

Once a decision has been made not to attempt CPR a form will be put in the individual's medical records. This is called a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form.

Who else will be involved in making the decision?

If the individual is very ill or lacks capacity, they might not be able to make decisions about their treatment and care. At this stage family and/or close friends may be asked if the individual has preferences or have made decisions about refusing or not wanting CPR.

It is important to remember that no one is able to make decisions for an adult with an intellectual and developmental disability.

Even if one of the individual's family or friends has been given a **Lasting Power of Attorney**, they cannot insist on CPR being used. This is a best interest decision made by the clinical team in the absence of any other legally binding decision.

Further information can be found at www.emas.nhs.uk/contact/care-decisions



ReSPECT.

The National Resuscitation Council (2017) is in the process of rolling out a national initiative 'The Recommended Summary Plan for Emergency Care and Treatment' (ReSPECT). ReSPECT is a process that creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices. It provides health and care professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person's care and treatment. ReSPECT should be part of a wider process of advance/anticipatory care planning.

The choices the patients make, or in the absence of capacity those made with the patient's next of kin, will be summarised on the designated documentation to support staff in providing care interventions chosen by the patient or in the patient's best interest. Planning with the patient where possible, what choices they would make should an emergency occur that threatens life. Conversations can be instigated at any point in a patient's care with staff from the many services across the Trust. However, there are delays in implementing ReSPECT because of the issues in not having a mandated tool to use nationally. Nottinghamshire Healthcare will monitor progress with the process and be ready to implement when agreement is reached regarding the documentation.

East Midlands Ambulance Service.

When you are caring for someone at home there might be a time when you feel that an ambulance needs to be called. Locally, East Midlands Ambulance Service (EMAS) gives emergency care to patients and transports them to hospital when necessary. EMAS have educated their staff about people with intellectual and developmental disabilities and all ambulance crews have a set of symbols which they can use to help communicate better with people with intellectual and developmental disabilities.

The ambulance service has a system in place so that healthcare professionals can inform them that someone has an end of life diagnosis. The system holds basic information based on the person's address. Detailed instructions as part of a care plan should be left in the patient's home. The system can register that a patient is not for resuscitation, does not wish to be transported to hospital for a specific condition, has a care team who should be contacted in the event of an ambulance attendance or has a specific care plan detailing wishes (a copy of which is with the patient).

The ambulance service will then check when they arrive at the home address and therefore be able to treat the patient appropriately and according to their wishes. The healthcare professionals involved in the patient's care must ensure that the ambulance service is notified of any changes, including when the patient has died.



Prognosis ‘a few weeks’

Continuing Healthcare.

NHS Continuing Healthcare is a package of care arranged and funded by the NHS to meet the physical and/or mental health needs caused by an individual’s illness. It can be provided in any setting including a care home, hospice or own home. A referral can be made by an appropriate healthcare professional.

For any individual with rapidly changing needs, there is a fast track process in place to ensure an appropriate care package can be arranged as quickly as possible. Once a care package is in place the individual will be formally assessed based on their individual needs, and an individual will receive ‘Continuing Care’ funding if assessed as having a primary health need.

The benefits an individual usually receives may be affected should Continuing Care funding be arranged. In some cases this may identify that NHS Continuing Care funding is not necessary for the ongoing care.

Most local continuing healthcare teams have registered nurses trained in intellectual and developmental disabilities to assess individuals.

An easier read information leaflet on Continuing Healthcare funding is available from the Department of Health.

[www.gov.uk/government/uploads/system/uploads/attachment_data/file/328377/
NHS_CHC_easy_read.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/328377/NHS_CHC_easy_read.pdf)



Medication and Anticipatory Prescribing.

Medication can be used to relieve symptoms and for pain relief. At the end of life stage consideration may be needed about how medication may be given. Medications should be reviewed regularly and may change on a regular basis.

Medications can be given via different routes and different forms:

Tablets: Some individuals with an intellectual and developmental disability may find it difficult to take tablets and this often becomes a problem for people at the end of their life. If you notice the individual chewing the tablet or having difficulty swallowing the tablet then this needs reviewing by the GP.

Liquids: Some medication can be given in liquid or syrup form; these may be easier for the individual to swallow but sometimes they can taste unpleasant.

Patches: Worn on the skin patches stay in place for several days and medication is absorbed via the skin.

Injection: Normally given by nursing staff

Syringe Driver: Some individuals at the end of their life may require a syringe driver; this is a small portable device with a fine needle that is inserted under the skin so that medication can be given easily to help symptom control.

Pain management:

Pain is only one symptom that's recognised at end of life; individuals may suffer other symptoms such as breathlessness, loss of appetite, problems with continence and constipation. It's important to remember that some individuals with an intellectual and developmental disability are unable to tell us if they are in pain, and they are therefore reliant on family, paid carers and professionals to be able to observe an individual's behaviour and note changes which may indicate distress.

**For useful tools used in
Nottinghamshire please see:**

***DisDAT Tool and
The Pain Profile***

Pages 22-23.

Once a baseline has been obtained to identify pain indicators it is important to monitor the effectiveness of any pain medications given and document this in the person's personal health file (orange section).



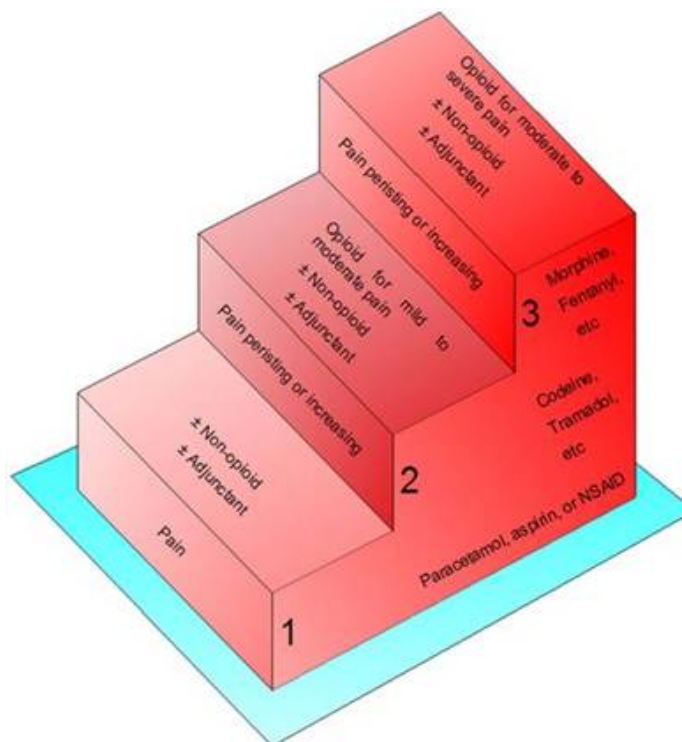
Drugs used to treat pain

Drugs used to treat pain (analgesics) work in different ways. Some work directly at the source of pain such as Paracetamol for headaches and some work indirectly such as Gabapentin.

The other group of medications to treat pain are known as Opioids such as Codeine or Morphine.

The individual's doctor will carefully plan a regime of pain management ensuring that levels of pain relief used are appropriate for the individual's level of pain. Below is a diagram showing how pain relief medication may step up in line with increasing pain. The World Health Organisation's Pain Relief Ladder, www.who.int/cancer/palliative/painladder/en/

WHO's Pain Relief Ladder



Side effects

There are three common side effects of pain medication, the nurse or GP can advise on treatments to help with these side effects.

Drowsiness	Usually wears off a few days after starting the medication.
Sickness	Gradually this should ease off after a few days but you can have an anti-sickness drug to take away these effects.
Constipation	Most people need to take a laxative when on pain medication to relieve this symptom.



Anticipatory prescribing

As an individual approaches their last few days of life, there may be a need for different medications to be available 'just in case' to ensure the individual is comfortable and pain-free during this time. The need for this medication may arise outside of the 'normal' operating hours of a GP practice but the individual may not want or need a hospital admission. Anticipatory prescribing allows medication to be prescribed before it is needed but to be kept in the home ready for when the time of need may come. The use of this medication will be assessed and managed by the health professionals involved.

Symptom	Medication
Agitation/delirium	Levomepromazine and/or Midazolam
Breathlessness	Morphine and/or Midazolam
Nausea or vomiting	<i>Cause known</i> — Cyclizine or Metrochloramide or Haloperidol <i>Cause unknown</i> — Levomepromazine
Pain	Morphine
Respiratory tract secretions	Hyoscine butylbromide

All medication should be reviewed on a regular basis and doses changed when necessary to ensure optimal symptom management.

Once medications are no longer required they should be taken to a pharmacy to be dispensed of in a safe manner. Some drugs will need to be checked and receipted by the pharmacist.



Prognosis < Than 1 week

Last days and hours for the person.

The last days and hours of an individual's life can be a scary time for all involved regardless of if the individual has an intellectual and developmental disability or not. It may be a time for some when 'reality hits' that a person they care for will not be around for much longer or a friend they spend time with will not be there anymore.

This section aims to answer some of the questions that may arise during this time and/or prepare family or paid carers on what may happen during these last days and hours.

During this time the individual's body and internal system will slowly be closing down and the organ performance will decrease.

As an individual approaches the end of their life some physical changes will occur, such as;

- Circulation slows. Fingers, toes and nose may become cold and change colour.
- Breathing pattern will change; may 'rattle'. Breathing slows down or becomes uneven.
- Fluid and dietary intake will be very little or none.
- Confusion may occur.
- Anxiety and behavioural changes may be present.

Five Priorities for Care.

When a person is likely to die in the next few days/hours there are five priorities of care that should be applied.

1. The change in the patient's medical condition is recognised and communicated clearly, decisions made and action taken in accordance with the person's needs and wishes. These are regularly reviewed and recorded in the patient's records.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of family and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care which includes food and drink, symptom control, psychological social and spiritual support is agreed coordinated and delivered with compassion.

Additionally the delivery of care must be based on and tailored to the needs, wishes and preferences of the dying person and, as appropriate, their family and those identified as important.



Things that may help.

Caring for an individual in their last days and hours can be distressing and emotional; the steps outlined below may help those involved in supporting the individual.

- Keep a contact sheet containing all the telephone numbers of people you may need to contact. (Please use the contact sheet included in this section).
- Obtain an explanatory letter from the GP; this may help if out of hours services need to be contacted.
- Be fully aware of any Advance Care Plans in situ, e.g. Do Not Attempt CPR.
- Keep in regular contact with those that have supported the person throughout and don't forget to express your own concerns or fears and get the support you need to continue your caring role.
- Reminisce good times that involve the individual, listen to their favourite music or watch their favourite TV programme.
- Spend quality time with the individual.

Last days and hours for others.

Everyone responds differently during the last days and hours of the life of an individual we care for, there is no right or wrong answer to reactions of coping in this situation.

Some people may:

- Cry and display emotions.
- Want to talk.
- Prefer their own space.
- Feel helpless and unable to function within their role.
- Need to act or do something.

Remember, try not to panic, it will be a distressing situation for all, don't feel as though you can't be upset but don't worry if the tears don't come and adrenalin takes over.



After Death

When a friend or family member dies.

It is normal to have a variety of emotions after death and different people handle things in different ways. There is no timescale for what an individual should feel and when. It may be that an individual has strong emotions immediately after the death of a loved one, but many individuals do not experience these emotions until much later on. Some individuals feel 'anticipatory grieving' where they have strong feelings such as loss and grief before the end of life.

An individual may want to share their feelings with family and friends, but equally, they may not feel comfortable doing this. Some people find it easy to talk to a particular individual – to express their thoughts and feelings freely.

This is no different for someone with an intellectual and developmental disability. Historically it's been believed that someone with an intellectual and developmental disability would not be able to understand or express grief. Therefore some family and staff members have not discussed the death of a family member or friend to someone with an intellectual and developmental disability to try and protect them and so as not to hurt their feelings (Blackman N Todd S, Caring for people with intellectual and developmental disabilities who are dying (2005) Worth Publishing).

How to support an individual with an intellectual and developmental disability:

- Be honest, be prepared to sit and talk to people (including those with no verbal communication) and use methods of communication most appropriate for the individuals (language, photos, books).
- Remember it's normal to feel unhappy/sad and hurt but be aware that the individual may need time for these feelings to manifest.
- Help the individual to think back on positive and enjoyable times 'Do you remember the time that....?'
- Someone with an intellectual and developmental disability may need more than one conversation to fully understand and accept what's happened.
- If you feel sad and upset don't hide this, this will help the individual with an intellectual and developmental disability realise this is a normal reaction to grief.
- Ensure the individual has support to continue with their normal daily lives whilst trying to adapt to living without their friend/family member around them (if this is something they want to continue with).
- Support the person to buy flowers, attend the funeral.
- Make a memory box or photo album about the individual to help remember the good and bad times.



What to do when someone dies.

<i>Action</i>	<i>Time</i>	<i>Date</i>	<i>Name</i>
Ensure death has been verified by an appropriate health professional.			
Take a note of the time for written records. Registered nurses are not required to certify death, they only need to document the facts, the time it occurred and who was present.			
Inform the GP or Out Of Hours (OOH) so the death can be certified.			
The doctor who certified death should provide a death certificate within the following few days after death. Check local policy.			
Consider if any person(s) would want to say their goodbyes.			
Contact any significant others (Friends/family)			
Inform any other residents (See purple section for further support).			
Inform any close staff members.			
Contact the undertaker.			
Register the death at the local registrars.			

This list may help to guide you when someone you care for dies. It may act as a reminder of who to contact and what may need to happen.



The Learning Disability Mortality Review (LeDeR) Programme.

The LeDeR programme has been set up as one of the key recommendations by The Confidential Inquiry into the Premature Deaths of People with a Learning Disability (CIPOLD).

CIPOLD reported that for every one person in the general population who dies from a cause of death amenable to good quality care, three people with learning disabilities will do so. More than a quarter of these were found to have a significant difficulty or delay in diagnosis, further investigations or specialist referral, and for a further quarter there were problems with their treatment.

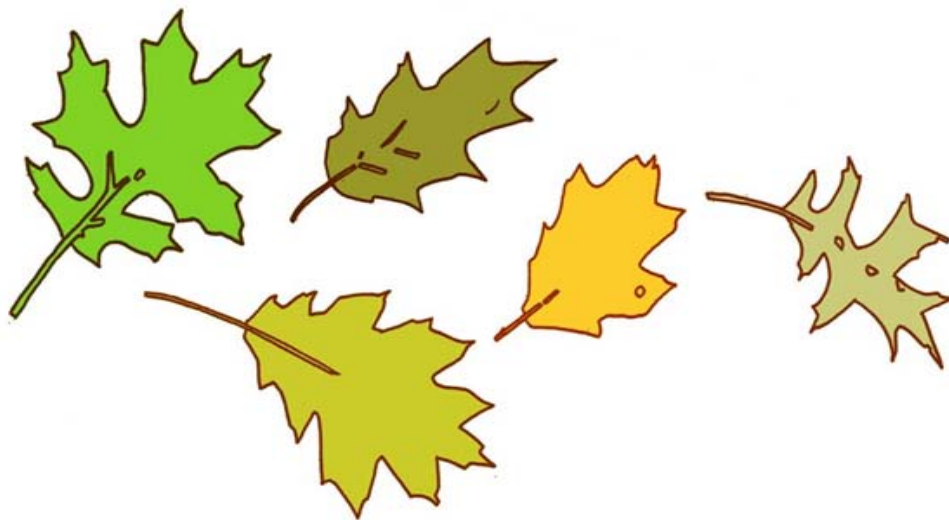
The LeDeR programme has been set up to contribute to improvements in the quality of health and social care for people with learning disabilities in England. It will do so by supporting local areas to carry out local reviews of all deaths of people with a learning disability, and for learning to be fed back into service improvements.

The focus of the reviews will be to:

- Identify potentially avoidable factors that may have contributed to a person's death.
- Identify differences in health and social care delivery across England and ways of improving services to prevent early deaths of people with a learning disability.
- Develop plans of action that will guide necessary changes in health and social care services in order to reduce premature deaths of people with a learning disability.

The LeDeR programme is supported by section 251 of the NHS Act (2006) for information sharing purposes. To make a death notification to LeDer please contact 0300 777 4774 or by accessing www.bris.ac.uk/sps/leder/notificationsystem/

Note: learning disability = intellectual and developmental disability.





Supporting the care guideline.

Appendices.

This section includes all the supporting documents and information that may be required, as outlined within the previous sections.

Appendix 1 Telephone contacts

Appendix 2 Person centred thinking diagram

Appendix 3 Directory of services

Appendix 4 Accessible resources

Appendix 5 Carer and professional resources

Appendix 6 Abbreviations



Appendix 1



Telephone contacts.

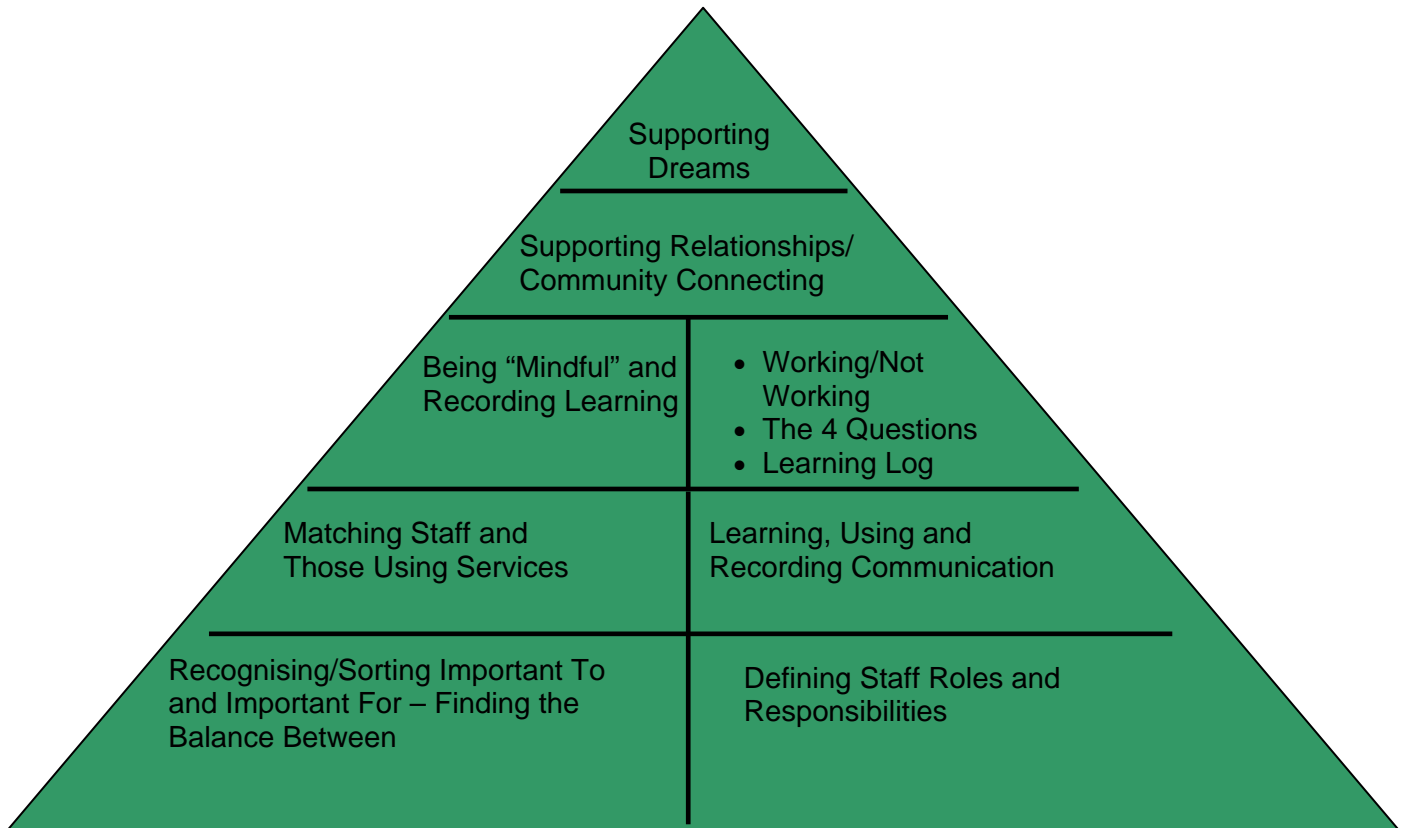
(Remove insert and display clearly near a telephone)

Service	Telephone Number	Contact Name (if applicable)
GP		
District Nurse		
Specialist Nurse		
Out of Hours		
Hospice		
Community Learning Disability Team		
Consultant		



Appendix 2

Person centred thinking diagram.





Appendix 3

Directory of services.

Primary Care Liaison Team (Intellectual and Developmental Disability)

Nottinghamshire County:

Department	Description of Services	Admission Criteria	Telephone Contact
Newark and Sherwood Newark Health Centre 14-22 Lombard Street Newark NG24 4XG	Primary Care Liaison Team are intellectual and developmental disability nurses who work across primary care. The team provides support to adults with intellectual and developmental disabilities, carers and professionals, to understand, maintain and improve their physical and mental health needs, whilst reducing identified health inequalities.	Adults with intellectual and developmental disabilities accessing primary care services.	01636 652500
Notts North and East Park House 61 Burton Road Nottingham NG4 3DQ			0115 961 7616
Nottingham West and Rushcliffe Stapleford Care Centre 4-16 Church Street Nottingham NG9 8DB			0115 883 5049
Mansfield and Ashfield Bull Farm Primary Care Centre Concorde Way Mansfield NG19 7JZ			01623 672183

Nottingham City:

Department	Description of Services	Admission Criteria	Telephone Contact
Intellectual and Developmental Disability Primary Care Team Clifton Cornerstone South Church Drive Clifton Nottingham NG11 8EW	Primary Care Liaison Team are intellectual and developmental disability nurses who work across primary care. The team provides support to adults with intellectual and developmental disabilities, carers and professionals, to understand, maintain and improve their physical and mental health needs, whilst reducing identified health inequalities.	Adults with intellectual and developmental disabilities accessing primary care services.	0115 883 4859

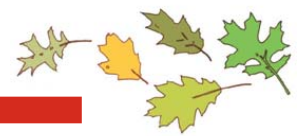


Intellectual and Developmental Disability Acute Liaison Nurses (County and City):

Department	Description of Services	Admission Criteria	Telephone Contact
Learning Disability Specialist Nurse King's Mill Hospital Mansfield Road Nottinghamshire NG17 4JL	Collaboration with the acute hospital to enable open and easy access to healthcare services for people with intellectual and developmental disabilities.	Adults with intellectual and developmental disabilities, using any clinics, theatres or inpatient facilities at either the King's Mill Hospital or Newark Hospital site.	01623 622515 Ext 6091
Acute Liaison Nurses Nottingham City Hospital Hucknall Road Nottingham NG5 1PB Queen's Medical Centre (QMC) Derby road Nottingham NG7 2UH	Collaboration with the acute hospital to enable open and easy access to healthcare services for people with intellectual and developmental disabilities.	Adults with intellectual and developmental disabilities, using any clinics, theatres or inpatient facilities at either the QMC or City site.	0115 924 9924 Ext: 62562
Acute Liaison Nurse Bassetlaw Hospital Blyth Road Worksop Nottinghamshire S81 0BD	Collaboration with the acute hospital to enable open and easy access to healthcare services for people with intellectual and developmental disabilities.	Adults with intellectual and developmental disabilities, using any clinics, theatres or inpatient facilities at Bassetlaw Hospital.	01909 502 933

Community Intellectual and Developmental Disability Teams (CIDDTs) - County

Department	Description of Services	Admission Criteria	Telephone Contact
Ashfield CIDDT 68 Portland Street Kirkby-in-Ashfield Mansfield Nottinghamshire NG17 7AG	Multi-disciplinary and multi-agency teams. Gate-keeper to needs led services. Transition Service for clients aged 16-18 available.	Age: 18+ (With the exception of the Transition Service) Level: Varying degrees of intellectual and developmental disability. Area: Living in the Ashfield Community.	0115 956 0882
John Eastwood Hospice Mansfield Road Sutton-in-Ashfield Nottinghamshire NG17 4HJ	Specialist palliative care.	24 hour telephone advice available for patients with an IDD who require end of life care.	01623 622626



Community Intellectual and Developmental Disability Teams (CIDDTs) - County

Department	Description of Services	Admission Criteria	Telephone Contact
Bassetlaw CIDDT Queens Building Potter Street Worksop S80 2BZ	As per previous page.	Age: 18+ (With the exception of the Transition Service) Level: Varying degrees of intellectual and developmental disability. Area: Living in the Bassetlaw Community.	0115 804 3100
Rushcliffe CIDDT Rushcliffe Day Centre Offices Loughborough Road West Bridgford Nottinghamshire	As per previous page.	Age: 18+ (With the exception of the Transition Service) Level: Varying degrees of intellectual and developmental disability. Area: Living in the Rushcliffe Community.	0115 876 0114
Gedling CIDDT Sir John Robinson Way Arnold Nottinghamshire NG5 6DB	As per previous page.	Age: 18+ (With the exception of the Transition Service) Level: Varying degrees of intellectual and developmental disability. Area: Living in the Gedling Community.	0115 876 0114
Mansfield CIDDT Meadow House Littleworth Mansfield Nottinghamshire NG18 2TB	As per previous page.	Age: 18+ (With the exception of the Transition Service) Level: Varying degrees of intellectual and developmental disability. Area: Living in the Mansfield Community.	0115 876 0114
Newark CIDDT Byron House Boundary Road Newark Nottinghamshire NG24 4DE	As per previous page.	Age: 18+ (With the exception of the Transition Service) Level: Varying degrees of intellectual and developmental disability. Area: Living in the Newark and Sherwood Community.	0115 876 0151



Community Intellectual and Developmental Disability Teams (CIDDTs) - City

Department	Description of Services	Admission Criteria	Telephone Contact
<p>Nottingham City North CIDDT Bulwell Riverside Main Street Bulwell Nottingham NG6 8QJ</p>	<p>As per page 50.</p>	<p>Age: 18+ (With the exception of the Transition Service) Level: Varying degrees of intellectual and developmental disability. Area: Living in the City.</p>	<p>0115 883 8588</p>
<p>Nottingham City South CIDDT Corner Stone South Church Drive Clifton Nottingham NG11 8EW</p>	<p>As per page 50.</p>	<p>Age: 18+ (With the exception of the Transition Service) Level: Varying degrees of intellectual and developmental disability. Area: Living in the Clifton Community.</p>	<p>0115 878 6270</p>



Appendix 4

Accessible resources

'About my friend: for friends of people with Down's syndrome and dementia' (IP)

Karen Dodd, Vicky Turk and Michelle Christmas

A picture booklet that outlines the dementia process and helps people with an intellectual and developmental disability understand what happens when a friend gets dementia.

Further information available at www.bild.org.uk

'Belly Ache'

Speak Up Self Advocacy

Accessible DVD for people with intellectual and developmental disabilities discussing gastro-intestinal cancer.

Further information available at www.friendlyinformation.org.uk

'Books Beyond Words'

- **Am I going to die?**
- **Getting on with cancer**
- **When Dad died**
- **When Mum died**
- **When somebody dies**
- **Going to the doctor**
- **Going to outpatients**
- **Going into hospital**

Royal College of Psychiatrists

A series of picture books developed for individuals with an intellectual and developmental disability.

Further information available at www.rcpsych.ac.uk

'Coping with Death'

Speak up Self Advocacy

This film shows a funeral and how to cope when someone a person cares for has died. It also helps a person to think about death.

Further information available at www.friendlyinformation.org.uk

'Death by Indifference' (easier read)

Mencap (2007)

A report of institutional discrimination within the NHS and individuals with an intellectual and developmental disability receiving poor healthcare.

Free to download from www.mencap.org.uk



'Decisions, Decisions'

A board game and accessible DVD for people with intellectual and developmental disabilities about the Mental Capacity Act produced by Speak Up Self Advocacy Group.

Further information at www.friendlyinformation.org.uk

'Going into hospital'

Speak Up Self Advocacy

This film is all about going into hospital.

Further information available at www.friendlyinformation.org.uk

'Let's Talk About Death'

Karen Watchman (2004)

A booklet discussing funerals and death.

Further information available at www.dsscotland.org.uk

'Living with an illness that I may die from'

Palliative care and people with intellectual and developmental disabilities (2009)

A series of information leaflets for individuals with an intellectual and developmental disability.

Available free from s.c.read@nur.keele.ac.uk

'Living with cancer' series

FAIR Multimedia

Illustrated series of booklets discussing cancer and the relating issues.

Further information available at www.fairadvice.org.uk

'Making a Will'

Speak Up Self Advocacy

This film for people with intellectual and developmental disabilities helps a person think about what may happen to their money and possessions after they die.

Further information available at www.friendlyinformation.org.uk

Resources available on a loan basis with the library at King's Mill Hospital.



Appendix 5

Carer and professional resources.

'Advice for Hospitals and Health Professionals'

Mencap (2008)

Tips for healthcare professionals when caring for a person with an intellectual and developmental disability.

Free to download from www.mencap.org.uk

'An Ordinary Death'

The Foundation for People with Intellectual and Developmental Disabilities (February 2003)

www.fpld.org.uk

'Cancer and People with Intellectual and Developmental Disabilities'

James Hogg, John Northfield and John Turnbull (2001)

A report commissioned by the Department of Health.

Order online from www.bild.org.uk

'Caring for People with Intellectual and Developmental Disabilities who are dying'

Noelle Blackman and Stuart Todd (2005)

Raises the awareness of everyone involved in enabling people with intellectual and developmental disabilities to be treated with respect and dignity as they approach death.

'Death by Indifference'

Mencap (2007)

A report of institutional discrimination within the NHS and individuals with a intellectual and developmental disability receiving poor healthcare.

Free to download from www.mencap.org.uk

'Delivering High Quality End of Life Care for People who have a Learning Disability'

Resources and tips for commissioners, service providers and health and social care staff. (2016)

A publication by NHS England in conjunction with the Palliative Care for People with Learning Disabilities Network.

Free to download from www.england.nhs.uk

'Dying Matters'

The Foundation for People with Intellectual and Developmental Disabilities (March 2005)

A workbook for staff supporting people with intellectual and developmental disabilities.

Order online from www.fpld.org.uk

'Equal Treatment: Closing the Gap'

Disability Rights Commission (2006)

A report of the formal investigation into physical health inequalities experienced by individuals with an intellectual and developmental disability.



'Feeling Better' (IP)

Dr Sharon McManus and Dr Brian McGuire

This resource pack is designed to provide practical guidance for health workers who work with people who have intellectual and developmental disabilities and chronic pain, includes a DVD.

www.pavpub.com

'Living with Intellectual and Developmental Disabilities, Dying with Cancer' (IP)

Irene Tuffrey-Wijne (2009)

Thirteen Personal Stories

'Loss and Learning Disability'

Noelle Blackman (2003)

Addresses how people with intellectual and developmental disabilities may be affected by the loss of a loved one.

'Making Reasonable Adjustments to End of Life Care for People with Learning Disabilities'

Public Health England 2014

The aim of this report is to make it easier for people to find and use reasonable adjustments, and to share good practice regarding the implementation of reasonable adjustments.

Free to download at www.ndti.org.uk

'Treat me right! Better healthcare for people with learning disabilities'

Mencap (2004)

A report calling for better healthcare provision for individuals with an intellectual and developmental disability.

Free to download at www.mencap.org.uk

'Valuing People. A New Strategy for Disability for the 21st Century'

Department of Health (2001)

This was the first White Paper on intellectual and developmental disability for thirty years and sets out an ambitious and challenging programme of action for improving services

Free to download at www.dh.gov.uk

'Valuing People Now. A New 3 Year Strategy for People with Learning Disabilities'

Department of Health (2008)

Valuing People Now sets out the Government's strategy for people with intellectual and developmental disabilities for the next three years following consultation.

Free to download at www.dh.gov.uk

Appendix 6

Abbreviations

ACP	Advance care plan
ADRT	Advanced decision to refuse treatment
CHC	Continuing healthcare
CIDDT	Community intellectual and developmental disability team
DNAR	Do not attempt resuscitation
EMAS	East Midlands Ambulance Service
EoL	End of life
GP	General Practitioner
HAP	Health action plan
HTLA	Hospital traffic light assessment
IDD	Intellectual and developmental disability
MDT	Multi-disciplinary team
NHSD	NHS Direct
OOH	Out of hours
PCP	Person centred plan
PPC	Preferred priorities of care
SPC	Specialist palliative care



Acknowledgements:

Version 1:

This resource pack was developed in 2011 as part of a project aimed at improving end of life care for people with an intellectual and developmental disability across Nottinghamshire County, Nottingham City and Bassetlaw. The project was originally funded by the National End of Life Care Programme.

The project in 2011 was led by:

Gemma del Toro, Primary Care Liaison Nurse (LD) , Nottinghamshire Healthcare

Claire Henley, Intellectual and Developmental Disability Nurse Specialist, Sherwood Forest Hospitals

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Version 2:

To recognise changes to practice both locally/nationally and to work in line with 'best ' practice this resource pack was updated in 2018.

The document update in 2018 was led by:

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यह दस्तावेज़ अनुरोध किए जाने पर अन्य भाषाओं और प्रारूपों में उपलब्ध है।

ਇਹ ਦਸਤਾਵੇਜ਼ ਬੇਨਤੀ ਕੀਤੇ ਜਾਣ ਤੇ ਹੋਰ ਭਾਸ਼ਾਵਾਂ ਅਤੇ ਰੂਪਾਂ ਵਿੱਚ ਉਪਲਬਧ ਹੈ।

در صورت درخواست این سند به زبانها و شکلهای مختلف در اختیار شما قرار می گیرد.

یہ دستاویز دیگر زبانوں اور مطلوبہ شکلوں (فارمیٹ) میں بھی دستیاب ہے

هذه الوثيقة متاحة بلغات أخرى وباشكال غير الكتابة المقروءة وذلك عند الطلب

**Specialist Palliative Care Outreach Team, John Eastwood Hospice,
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