



GUIDELINES AND AUDIT
IMPLEMENTATION NETWORK

Guidelines for Palliative and End of Life Care in Nursing Homes and Residential Care Homes

December 2013

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Section 1: Introduction

1.1 Introduction to the Guidelines

Nursing and residential care homes are increasingly the place where people nearing the end of life will live and be cared for until their death. Many of these people are living with multiple chronic conditions, and therefore require more complex interventions. The population of Northern Ireland is becoming increasingly older. By 2020, the number of people over the age of 75 years is expected to increase by 40%, with those aged 85 and over expected to increase by 58%.

Historically, people with cancer predominantly accessed palliative care. However, it is increasingly recognised that those living with advanced non-malignant diseases may also benefit from access to palliative care regardless of care setting¹. Given that the prevalence of chronic conditions and dementia increases with age, demand for palliative and end of life care services is likely to increase as the population ages and more people live with the consequences of physical and/or cognitive frailty. The average length of stay has now reduced significantly with many residents' conditions deteriorating much more quickly, adding to the complexity and higher dependency levels within care homes.

These guidelines build upon what has already been achieved with the implementation of the DHSSPS Nursing Home and Residential Home minimum standards.^{2,3} These guidelines will build upon what has already been achieved and are not intended to replace existing clinical guidance but rather provide best practice regarding systems and processes. They should be used in conjunction with current palliative care clinical guidelines including Palliative Adult Network Guidelines⁴ and General Palliative Care Guidelines for the Management of Pain at the End of Life in Adult Patients.⁵

The guidance in Section 1 is aligned to the following:

Palliative and End of Life Care Competency Framework

- Overarching Values and Knowledge
- Communication Skills
- Assessment and Planning

¹ Department of Health Social Services and Public Safety (DHSSPS) (2010) *Living Matters Dying Matters, A Palliative and End of Life Care Strategy for Adults in Northern Ireland*. Belfast: DHSSPS available online: www.dhsspsni.gov.uk/8555_palliative_final.pdf

² Department of Health Social Services and Public Safety (2008) *Nursing Homes Minimum Standards*. Belfast: DHSSPS

³ Department of Health Social Services and Public Safety (2011) *Residential Care Homes Minimum Standards*. Belfast: DHSSPS

⁴ Watson, M., Lucas, C., Hoy, A., Back, I. & Armstrong, P. (2011) *Palliative Adult Network Guidelines* 3rd Edition

⁵ Guidelines and Audit Implementation Network, (2011) *General Palliative Care Guidelines for the Management of Pain at the End of Life in Adult Patients*. GAIN: Belfast. available online:

Policy Context

The aim of these guidelines is to enable staff within the nursing and residential care home setting, in collaboration with other members of the health and social care team, to provide consistent high quality palliative and end of life to residents and their families. The guidelines are designed to support the minimum care standards for nursing and residential homes; and regional strategic documents which promote continuous quality improvement including:

- Living Matters, Dying Matters A Palliative and End of Life Care Strategy for Adults in Northern Ireland.¹
- Transforming Your Care: A Review of Health and Social Care in Northern Ireland.⁶
- Palliative and End of Life Care Competency Assessment Framework.⁷
- End of Life Care Operational System (Appendix 2).⁸
- Locally Enhanced Service Advance Care Planning for General Practitioners.⁹

Many people, particularly those with non-cancer conditions, do not have palliative care needs identified. Therefore, symptoms are not controlled and services not provided. People with cancer generally have a much better quality of life in the last year because their palliative care needs are identified and managed appropriately. The End of Life Care Operational System is a tool or an aide memoir to support HSC professionals when identifying and planning end of life care for those who are approaching the last year of life irrespective of condition. This system aims to improve the quality of care in the last year of life and provides a guide which supports clinicians when identifying and planning palliative and end of life care.

If someone is thought to be possibly in the last year of life, various actions should take place such as holistic assessment, and the opportunity to develop an advance care plan when appropriate. At this stage acute and palliative care should complement each other thereby ensuring individuals have an improved quality of life and can still be admitted to hospital for acute treatment when necessary.

When someone is definitely identified as being in the last few weeks or months of life, the approach to their care should primarily be palliative and include appropriate planning and anticipation of future care needs. The care home must develop and document an agreed plan which includes “preferred place of care”, out of hours handover, anticipatory prescribing etc.

1.2 Implementation and Monitoring

RQIA expects each nursing and residential home to demonstrate a planned approach to implement the best practice points contained within these guidelines. The self assessment audit tool will enable each home to undertake a baseline self assessment, identify and action areas for improvement and monitor ongoing progress (Appendix 3).

www.gain-ni.org/Publications/Guidelines/Gain%20pain%20final.pdf

⁶ Department of Health Social Services and Public Safety (2011) *Transforming Your Care: A Review of Health and Social Care in Northern Ireland*. Belfast: DHSSPS available online:

<http://www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf>

⁷ Health and Social Care (2012) *Palliative and End of Life Care Competency Assessment Tool* Belfast: HSC

⁸ Health and Social Care Board/ Public Health Agency (2012) *End of Life Care Operational System (ELCOS)* Belfast: Public Health Agency

⁹ Health and Social Care Board (2012) *Northern Ireland Local Enhanced Service: Advanced Care Plans in Nursing Homes 2012-13* http://www.hsccbusiness.hscni.net/pdf/LES_Nursing_Homes_Policy.pdf

Furthermore, HSCB/HSCT contracts with nursing and residential homes should reflect these guidelines as a measure of expected high quality palliative and end of life care.

1.3 Understanding Palliative and End of Life Care within the Context of Nursing and Residential Care Homes

Registered nursing homes and residential care homes in Northern Ireland vary in size and range from small proprietor managed single homes to larger facilities owned by organisations. Initial placement and ongoing support of the person, family and nursing or residential home is facilitated by care management both locally and regionally.

In nursing homes, nursing care is provided by in-house nursing staff and medical support is offered by General Practitioners (GPs). Nursing home staff are supported in some Trust areas by Trust nursing services, however, this varies from Trust to Trust.

Residential care homes on the other hand provide personal and social care by non-clinical in-house care staff. Medical support is provided by GPs and nursing support in these settings is accessed via district nursing services within each Trust area.

The context within which care is provided in nursing and residential homes is very important. The ethos of homes is generally to provide a 'home' environment in which the person lives, a 'home from home'¹⁰ where their relatives and friends are welcome and the emphasis of care is on 'rehabilitative living'.¹¹ However, this approach is increasingly alongside the provision of a care environment where residents die. The profile of individuals living in nursing and residential care homes has changed significantly in the last number of years. Many residents are now living with multiple chronic illnesses including dementia.^{12,13} The average length of stay has reduced significantly, with many residents being admitted much later in the stage of their illness, leading to higher dependency levels and increasingly complex care needs.¹⁴ This 'living versus dying' context makes caring for residents more complex with a continuous balancing act for staff between supporting the living and managing the dying. The value placed on the nursing home being a 'home' may also create difficulties for staff who perceive their residents as 'family' and therefore decisions about end of life care may be more difficult.

Palliative care has traditionally been offered to people with cancer.¹⁵ However, it is increasingly recognised that access to palliative care may also benefit those living with advanced non malignant diseases regardless of care setting.¹⁶ The vast majority of residents in nursing and residential homes who have palliative care needs may never need to be referred to specialist palliative care and in fact do not meet the criteria for referral to such services.¹⁷ They do, however, require general palliative care and a palliative approach which recognises and respects the unique individuality of the person being cared

¹⁰ Froggatt KA (2001) Palliative care and nursing homes: Where next? *Palliative Medicine* 15:1 42–8

¹¹ Komaromy, C. (2002). The performance of the hour of death. In: Hockley, J and Clark, D (eds) *Palliative care for older people in care homes. Facing Death*. Ch. 8. Milton Keynes: Open University Press

¹² Komaromy, C., Sidell, M., Katz, J.T. (2000) The quality of terminal care in residential and nursing homes. *International Journal of Palliative Nursing* 6:4 192-200

¹³ Forbes, S. (2001) This is Heaven's waiting room. *Journal of Gerontological Nursing* 27:11 37-45

¹⁴ Stein, W.M. (2001) Pain management in the elderly *Clinical Geriatric Medicine* 17:3 575-594

¹⁵ Addington – Hall J. & Higginson, I. (2001) *Palliative Care for Non-Cancer Patients* Oxford: Oxford University Press

¹⁶ House of Commons Health Committee (2004) *Palliative Care. Fourth Report of Session 2003-04*. London: House of Commons.

¹⁷ Kinley, J. & Hockley, J. (2007) A baseline review of medication provided to older people in nursing care homes in the last month of life. *International Journal of Palliative Nursing*. 16:5 216-223

for, thus providing person centred care within the nursing and residential home setting. It includes both the person and those that matter most to them.

1.4 Adopting a person centred approach

Person centred care is focused on respecting and valuing each person as a unique individual with rights. This involves engaging with others in a way that promotes their dignity, sense of worth and independence. It is about working with residents on the things that are important to them without the restraint of rituals and routines.¹⁸

The guidelines reflect the person centred approach required to deliver palliative and end of life care, and are underpinned by the following core values which have been informed by the Minimum Standards for Nursing and Residential Care Homes.^{2, 3}

1.4.1 Dignity and respect

The uniqueness and intrinsic value of the individual person is acknowledged and each person is treated with respect.

1.4.2 Independence

Individuals have as much control as possible over their lives whilst being protected against unreasonable risks.

1.4.3 Rights

The person's individual and human rights are safeguarded and actively promoted within the context of services delivered by the home.

1.4.4 Equality and diversity

Individuals are treated equally and their background, special or additional needs and culture are valued. The services provided by the home fit within a framework of equal opportunities and anti-discriminatory practice.

1.4.5 Choice

Individuals are offered, wherever possible, the opportunity to select independently from a range of options, based on clear and accurate information. This may require making reasonable adjustments to communication to and from the person throughout the care and treatment process.

1.4.6 Consent

Individuals have a legal right to determine what happens to them and their informed, genuine and valid consent to the care, treatment and support they receive is essential.

1.4.7 Fulfilment

Individuals are enabled and supported to lead full and purposeful lives, and realise their ability and potential.

¹⁸ Health Service Executive (2010) Enhancing Care for Older People - A Guide to Practice Development Processes to Support and Enhance Care in Residential Settings for Older People. Dublin: HSE

1.4.8 Safety

Individuals feel as safe as possible in all aspects of their care and life, and are free from exploitation, neglect and abuse.

1.4.9 Privacy

Individuals have the right to be left alone, undisturbed and free from unnecessary intrusion into their affairs and there is a balance between the consideration of the person's own and others safety.

1.4.10 Confidentiality

Individuals know that information about them is managed appropriately and will not be disclosed without permission, except when required by legislation or the need to protect the well-being of others.

A practice development approach which is supported by management is required to enable and empower staff within the homes to adopt a person centred approach to care which is effective and sustainable. Skilled facilitation is essential to enable staff to reflect on their practice and develop their skills to ensure they are compassionate and competent in delivering end of life care in accordance with their individual roles.

1.5 Support for family and those that matter to the person

Caring for the family is a fundamental, but often complex, part of caring for the person at the end of life. The family may be defined as:

“... those closest to the patient in knowledge, care and affection. This includes the biological family, the family of acquisition (related by marriage/contract) and the family of choice and friends (not related biologically, by marriage contract)”¹⁹

Based on the above definition, it seems reasonable to consider that ‘family’ might include carers, friends, neighbours, and indeed staff within the home. This definition extends the boundaries of ‘family’ beyond that of biological and legal relationships. It also highlights that a person considered as ‘family’ by a resident might not be a relation by birth or marriage.

Along with facilitating and supporting ongoing relationships between the person and those that matter to them, staff in the homes must be aware of, and often negotiate through difficult and strained relationships between family members whilst meeting their needs and those of the resident. Where people are regular visitors to the home, and where a partnership approach to caring for the person has been established, staff in the home will have developed a relationship with the family and will therefore be able to provide support and care to them as necessary. However, different people will have different relationships with staff in the home. They may also have different support needs, depending on where they live, what other support they have available to them, their age and health status, religious and cultural needs. Consideration needs to be given to how best to communicate and support these people too.

¹⁹ Canadian Palliative Care Association (1998) *Standards for Palliative Care Provision*. Available online at: www.chpca.net/home.htm

1.6 Availability of Services

Easy access to statutory and voluntary services is essential if staff in nursing and residential care homes are to achieve best practice in end of life care for their residents and families. It should however be noted that services vary across all localities and therefore the homes need to be aware of local service availability.

1.6.1 Role of the General Practitioner (GP)

All residents living in nursing and residential homes must be registered with a GP. The role of the GP in nursing and residential homes is to work closely and collaboratively with staff to ensure the holistic needs of the resident are met. The GP is responsible for:

- Medical assessment and management of the individual including onward referral for investigation and diagnostic services,
- Early identification, assessment and advanced care planning in partnership with the key worker and other staff in the home, as per the locally enhanced service contract,⁹
- Inclusion of the individual on the palliative care register as appropriate and communication of this to trust key worker for inclusion on trust held register if the person is also in receipt of trust services,
- Drug prescribing for actual problems,
- Anticipatory drug prescribing for potential problems,
- Liaison and onward referral to multidisciplinary team and specialist services,
- Certification of death and notification of coroner where indicated,
- Communicating with the family and staff in the home.

1.6.2 Role of the Multidisciplinary Team

Care Management: The care management role may be undertaken by a range of professionally qualified staff in social work and health with appropriate training skills and experience.²⁰

The role of the Care Manager is to:

- Act as a main contact for the person/family
- Provide information to the person and the family on a range of homes most appropriate to their assessed needs
- Ensure all financial implications are discussed with the person and family and choice has been offered
- Provide guidance to the person and family to assist in their decision making of end of life care.
- Collate and provide a range of professional assessments to the Nursing and Residential Homes to facilitate admission and care planning
- Undertake a Carers' Assessment
- Ensure that regular Care Management Reviews are carried out in a timely manner or as needs change
- Co-ordinate and share information within and between primary, community and secondary care services throughout the placement

²⁰ Department of Health Social Services and Public Safety (2010) Care Management, Provision of Services and Charging Guidance. Circular HSC (ESSU) 1/2010. Belfast: DHSSPS

- Facilitate risk assessment within the nursing and residential care setting in accordance with quality standards and address any issues or complaints that may arise during the placement.

Nursing Care: in Nursing Homes is provided predominantly by staff in the homes. In some areas district nurses provide additional support to nursing homes. It is therefore worthwhile to check local policy in your area.

District Nurse: Services include:

- Holistic nursing and palliative care assessment;
- Advice and symptom management;
- Blood tests (for example INR tests for warfarin monitoring);
- Wound management;
- Management of catheters;
- Continence assessment;
- Provision of nursing equipment;
- Management of syringe drivers.

Community Occupational Therapist²¹: The role of the community occupational therapist within nursing and residential care homes includes an evidence based holistic approach to enable the individual to participate in the activities of everyday life. This is achieved by working with the individual and staff in the home to enhance the person's ability to engage in the activities they want to, need to, or are expected to do. Occupational therapists also modify the environment to better support the person's needs.

Examples of how this is achieved within nursing and residential homes include:

- Assessment of activities of daily living e.g. bathing, toileting, dressing, feeding;
- Wheelchair assessment and provision of appropriate wheelchair;
- Seating and pressure relief assessment and provision or advice on purchase of appropriate chairs and cushions;
- Advice on appropriate feeding aids;
- Advice on small aids to promote independence e.g. helping hand, long handled shoehorn, tights aid;
- Postural and positioning assessment and advice;
- Fatigue management;
- Relaxation therapy.

Community Physiotherapist²¹ The role of the physiotherapist within nursing and residential care homes includes an evidence based holistic approach in the preventative, diagnostic and therapeutic management of disorders of movement or optimisation of function, to enhance the health and well-being of the individual.

²¹ Department of Health Social Services and Public Safety (DHSSPS) (2012) Improving Health and Wellbeing through positive partnerships: a Strategy for Allied Health Professionals in Northern Ireland 2012-17. available at: <http://www.dhsspsni.gov.uk/ahp-strategy-feb-2012.pdf>

Physiotherapy interventions within nursing and residential care homes include:

- Postural and positioning assessment and advice;
- Therapeutic exercises to improve mobility, strength and /or function;
- Management of respiratory symptoms including breathlessness and retained secretions;
- Fatigue management;
- Relaxation therapy;
- Lymphoedema prevention and treatment and education/advice to care workers;
- Manual handling assessment and advice;
- Advise on aids e.g. walking sticks, rollators, slings, joint supports.

Community Dietitian²¹ Community dietitians assess, diagnose and treat the diet and nutrition problems of individuals using evidence based practice, and a holistic approach to enable the person to make appropriate lifestyle and food choices including therapeutic diets.

Within nursing and residential homes, the community dietitian will:

- Assess, diagnose and treat diet and nutrition problems, with aims of care determined by the phase of palliative care.
- Devise eating plans for residents for the management of medical conditions such as diabetes, renal insufficiency and coeliac disease;
- Support residents and their carers in making appropriate food choices in order to maintain optimum nutrition to maintain function;
- Limit unnecessary food restrictions so that optimal choice is available;
- Ensure that where nutrition screening is carried out and nutritional support is provided it is appropriate to the aims of care. For example, in early palliative care the aim of care is to reduce or prevent malnutrition, however in last weeks and days of life the aims of care are to provide comfort and improve quality of life. Therefore screening or comment of oral nutritional supplements may not be clinically appropriate at this time.

(informed by Strategy for Allied Health Professional Northern Ireland).²¹

Community Speech and Language Therapist²¹ The role of the Community Speech and Language Therapist within nursing and residential care homes is to use evidence based practice, and a holistic approach to enable individuals to maintain optimal communicative and /or swallowing function, as the person's condition changes or deteriorates.

Speech and Language Therapy interventions within nursing and residential homes may include:

- Provision of timely and comprehensive assessment, diagnosis and treatment of speech, language, communication and swallowing problems. Assessment of communication may provide valuable information regarding a person's capacity/consent for interventions;
- Education of staff members regarding the management of an individual's communication and/or swallowing disorder;

- Advice regarding the adaptation of a person's communicative environment to reduce social isolation, communication anxiety and avoidance. Facilitation of a patient's communication to enable informed decision making;
- Provision and teaching on the use of an alternative or augmentative communication system where oral communication is limited or precluded by a physical condition;
- Provision of compensatory strategies to an individual to maximise independence in communication and/or swallowing;
- Recommendation of appropriate consistencies of food and drink and advice regarding feeding method, to minimise aspiration risk, maximise function, choice and independence, whilst allowing the individual to maintain pleasure in eating and drinking;

(informed by Strategy for Allied Health Professional Northern Ireland)²¹

Dentist: The Dentist can assist staff in the Homes to maintain quality of life for residents through the assessment and management of oral health problems.

Within nursing and residential homes, the dentist can:

- Assess oral health of the individual
- Diagnose oral problems
- Offer an individualised plan of treatment, and provide treatment where appropriate
- Assist with the management of oral pain, and other conditions such as dry mouth
- Refer on to specialist dental services if appropriate, or obtain specialist advice where patient referral is not appropriate
- Liaise with other professionals involved in the patient's care and management
- Offer advice to the resident, family and staff in the home regarding ongoing oral care

Community Pharmacist: Community Pharmacists can be very helpful in organising medicines for residents and will usually:

- Order repeat medication;
- Pick up prescriptions from the GP;
- Deliver medicines to the care home.

In addition community pharmacists can offer advice regarding:

- Alternative medication routes;
- Drug interactions;
- Simple over the counter treatment of minor illness.

Clinical Nurse Facilitator for Nursing Homes: The role of the Clinical Nurse Facilitator for nursing homes exists across the majority of Trusts within Northern Ireland. However, the focus of the role varies from Trust to Trust and includes:

- Specialist tissue viability service;
- Regular education, support and guidance;
- Forum for the nurse managers;
- Clinical supervision;
- Peer support.

1.6.3 Specialist Palliative Care Services, including Hospice Services

Specialist palliative care services provide complex holistic palliative and end of life care, respite and rehabilitation. These services are provided by both statutory and voluntary sector organisations and support primary, community and secondary care general palliative care services. Specialist Palliative Care Services include:

- Community Specialist Palliative Care Multidisciplinary Teams which comprise of Palliative Care Consultant, Specialist Nurses, Physiotherapist, Occupational Therapist, Dietitian, Chaplains, Speech and Language Therapist and Social Worker;
- Hospice specialist palliative care in-patient beds, day hospice and palliative care outpatient services;
- Education and training,²²

The role of the specialist community palliative care team includes:

- Assessment of complex symptoms;
- Specialist advice and guidance on symptom management;
- Advice on the management of syringe drivers and drugs used;
- Holistic assessment and support for patients and carers;
- Signposting to other relevant services;
- 24hour telephone advice to professionals;
- Pre and post bereavement care;
- Education and training to patients, families and other health professionals,
- Multidisciplinary clinical interventions e.g. lymphoedema management and fatigue management
- Complex discharge planning

1.6.4 Role of the Key Worker in the Nursing and Residential Home^{1, 23}

The key worker role is a new regionally agreed role which aims to ensure communication and co-ordination to ensure maximal quality of life in the last year of life and support the person to remain in their preferred place of care. It is an integral part of the role of all relevant health and social care professionals. The individual who assumes the key worker function will be a member of the person's multidisciplinary team, responsible alongside other team members, for planning and co-ordinating patient care across interfaces, including within and between care teams and care settings.

Although it is recognised that in many areas, individuals are already allocated a key worker; to ensure consistency and equity of care, each health and social care provider will need to consider how the palliative care key worker function is allocated, and how it may be transferred depending on the needs of the person/family.

The key worker role in the residential care home may be assumed by the district nurse, social worker, care manager or other member of the multidisciplinary team dependant on the needs of the person.

²² Health and Social Care Board (2012) *End of Life Care Commissioning Specification*. Belfast: HSCB.

²³ Health and Social Care/ Public Health Agency (2011) *Definition and Competencies for Key Worker Function*. Belfast: HSC / PHA

Many nursing homes already operate a named nurse/key worker system. Whilst this extended key worker role may be assumed by a registered nurse in the home, this may not always be the case and will be dependant on the individual needs of the person and their family. The key worker should be identified and recorded when it is recognised that the person has palliative care needs and is placed on the palliative care register. This decision should be discussed and agreed as part of the multidisciplinary approach, respecting individual preference and considering continuity of care. This role should be transferable between members of the multidisciplinary team depending on the different stages of the illness.

Role and Responsibilities of the Key Worker ²³

It is anticipated that the role and responsibilities within the key worker function should include the following:

- Act as a main contact for the person/family;
- Facilitate decision making and end of life care planning, taking into consideration who is the best person to do this;
- Ensure the appropriate communication/discussions take place at the person's pace to allow them to have an active and informed role in their care planning;
- Provide information and guidance to other professionals relating to the patient and their carer;
- Co-ordinate patient and carer assessments, referrals and multidisciplinary team care planning;
- Ensure that assessment, review and update of care plans takes place so that symptoms are managed and physical, emotional, and spiritual needs are met;
- Co-ordinate and share information within and between primary, community and secondary care services;
- Ensure that systems and processes are in place to ensure handover of information on a 24 hour basis to all relevant services;
- Ensure family and carers are aware of who to contact on a 24/7 basis for advice and support;
- Ensure that the carer/significant others' needs have been assessed (e.g. carer assessment);
- Ensure that families and carers are supported as necessary including what symptoms and signs to look out for and how these should be managed;
- Ensure that the goals of care are agreed and implemented;
- Co-ordinate bereavement follow up.

Resources

National Council for Palliative Care/ End of Life Care Programme (2007) Building on Firm Foundations: Improving End of Life Care in Care Homes: Examples of Innovative Practice. Available online at:

http://www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_Building_on_firm_foundations.pdf

RCN website hosts a large amount of guidance around Team working which can be accessed through the publications section of the website:

<http://rcn.org.uk/development/publications>

Nursing Midwifery Council (2008) The Code: Standards of Conduct, Performance and Ethics for Nurses and Midwives.

Available on line at:

http://www.nmcuk.org/Documents/Standards/nmcTheCodeStandardsofConductPerformanceAndEthicsForNursesAndMidwives_TextVersion.pdf

A series of common clinical scenarios which consider the various ethical principles can be found in: Watson, M., Lucas, C., Hoy, A., Back, I. & Armstrong, P.(2011) Palliative Adult Network Guidelines 3rd Edition Chapter 35 Ethics and Communication pp257-264

Hospice Friendly Hospitals (2011) Introduction to the Ethical Framework for End of Life Care available online at:

<http://www.hospicefriendlyhospitals.net/media/pdfs/Ethical%20Framework.pdf>

Eight, one hour study sessions based on the framework are also available by following the links on the website.

Section 2: Identification of the Stage of Illness

2.1 Identification of the Stage of Illness

Approximately 15,000 people die in Northern Ireland every year; two thirds of whom would benefit from a level of palliative care during the last year of life but for reasons of diagnosis are excluded.²⁴ Although some deaths are unexpected, many others can, in fact, be predicted. This can be particularly difficult within the nursing and residential care home sector, where the majority of residents are likely to have multiple co-morbidities. However, it is important to remember that, multiple co-morbidities are of themselves a poor prognostic indicator.⁹

Three triggers that suggest when patients are nearing the end of life are:^{8,25}

1. The surprise question: "Would you be surprised if this patient were to die in the next year, few months, weeks, days?"
If you wouldn't be surprised, what should you do to ensure that everything is ready, just in case they deteriorate quickly? (see ELCOS).⁸
2. General indicators of decline/deterioration increasing the need or choice for no further active care.
3. Specific clinical indicators related to certain conditions.

Earlier identification of those individuals who may be in the last year of their life leads to earlier planning and better care. Appropriate supportive care measures can be introduced which enables earlier discussion of the person's wishes, improves care which is aligned to their preferences and leads to fewer crises. Recognising and talking about what matters is important for most people, and requires partnership working between health and social care professionals, the person and those that matter most

The guidance in Section 2 is aligned to the following:

Palliative and End of Life Care Competency Framework

- Overarching values and knowledge
- Communication Skills
- Assessment and Care Planning
- Advance Care Planning

Living Matters, Dying Matters

End of Life Care Commissioning Specification

²⁴ National Council for Palliative Care (2005) *Focus on Policy Branching Out*. London: NCP.

²⁵ Gold Standards Framework (2011) *The GSF Prognostic Indicator Guidance*. 4th Edition available online at www.goldstandardsframework.org.uk/TheGSFToolkit/ToolsandTemplates

to them.¹ However, it is important to recognise that some people do not wish to discuss their future care needs, and their wishes should also be respected.

Earlier identification of those individuals who may be nearing the end of their life will assist staff to anticipate the person's likely palliative care needs, thus ensuring the right care can be provided at the right time. This requires a co-ordinated approach between the various health and social care service providers and may be supported by the use of a palliative care register.

Inclusion on the palliative care register does not mean that acute care is no longer appropriate. In fact, acute and palliative care can take place at the same time and is often required for the management of symptoms.

Best practice

1. The home holds a **Palliative Care Register** and has a system in place to ensure this is updated regularly, and communicated to all staff in a timely manner.
2. Staff within the home hold regular review meetings in order to ensure early identification of stage of illness/ palliative and end of life care needs of individual residents and their families.
3. Identification of palliative and end of life care needs is communicated to the person's GP and other members of the multidisciplinary team, as appropriate, in a timely manner. Staff in the home, the GP and other members of the multidisciplinary team, jointly agrees when the resident should be considered for inclusion on the palliative care registers which are held in the home and GP surgery.
4. The GP, staff in the home and the key worker communicates effectively and sensitively with the person and their family to ensure they are aware of the palliative nature of the individual's condition and to identify specific needs and concerns. Consent will be sought from the person (if appropriate) and their family prior to inclusion onto the palliative care registers held in the home and GP surgery.
5. The person's key worker communicates effectively with all members of the multidisciplinary team caring for the individual resident.
6. A holistic assessment of the person's needs is carried out on admission and reviewed at regular intervals throughout the residency. This is then used to plan implement and evaluate care.
7. All information pertaining to the assessment, planning and evaluation of care is clearly documented in the person's health record.
8. Referrals to other services, including specialist palliative care services are made, dependant on individual assessed need.
9. Inclusion on the palliative care register prompts the GP, staff in the home and the key worker to consider the need for an advance care planning discussion, if this has not

already taken place. This should be offered within three months of admission to the nursing or residential care home.²²

10. Where the person is considered to be definitely in the last months or weeks of life, staff in the home will liaise with the GP to ensure there is written information available within the Home regarding the person's Do Not Attempt Resuscitation Status, Out of Hours handover form is completed, unnecessary medication is discontinued and alternative anticipatory medication prescribed and available when appropriate.
11. If possible, those individuals who are considered to be in the last months or weeks of life, and whose death may be required to be communicated to the coroner, are identified. The GP discusses this with the person (if appropriate) and their family in a sensitive and timely manner prior to the person's death.

2.2 Decision Making

Ethical issues often arise in palliative and end of life care and can be fraught with difficulty in an increasingly technological age, where the process of dying may be prolonged²⁶. In health and social care, there is often no right or wrong decision, but only a consensus view of a clear aim, considered on the basis of the Human Rights Act 1998 and the four ethical principles below:⁴

Autonomy	the person should be informed and involved in the decision making process
Beneficence	do good
Non- maleficence	do no harm
Justice	balance the needs of the individual with those of society

Applying these principles in practice is often far from simple and requires excellent communication between all professionals involved in the person's care, the person and their family. The essence of ethical practice at all levels requires clear consideration of the legal, ethical and professional standards required and how these can be applied compassionately to the challenges of clinical practice.

Best Practice

1. The person and their family are given clear information regarding care options and possible outcomes in order to make an informed decision in relation to changing the goals of care. The information is communicated sensitively and in a manner that is easily understood. The person and their family are given the opportunity to discuss and clarify any concerns.
2. Where possible, the person is involved in the decision making process regarding changing the goals of their care.
3. Where it is not possible to include the person in decisions regarding their care (e.g. where they are unable to communicate), decisions will be made in their best interests and their previously known wishes will be taken into consideration. Their family will be included in the decision making process.

²⁶ GMC (2010) Treatment and care towards the end of life: good practice in decision making. Available online at http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf

4. Decisions are communicated clearly within the care team and across the wider multidisciplinary team as appropriate.
5. Decisions are clearly documented in the person's health record.

Useful Tools/Templates

The Gold Standards Framework website has very useful information regarding the systems and processes needed to ensure high quality palliative and end of life care which can be downloaded from the GSF Toolkit section of the website

Useful templates including sample Palliative Care Register and Advance Care Planning Discussion template are available online at:

<http://www.goldstandardsframework.org.uk/TheGSFToolkit>

“This is me” leaflet is a type of patient passport, developed by Alzheimers Society and Royal College of Nursing. It is intended to provide professionals with information about the person with dementia, as an individual. This will enhance the care and support given while the person is in an unfamiliar environment and can be used across care boundaries, to assist person centred care.

For this and other useful information regarding dementia which includes a large number of factsheets which can be downloaded free of charge, go to: <http://www.alzheimers.org.uk>

Resources

NI Direct website hosts useful information regarding Referral to Coroner

Information can be accessed at www.nidirect.gov.uk/coroner-post-mortems-and-inquests

The General Medical Council provides guidance on decision making regarding end of life care. Information can be accessed at http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf

GSF Prognostic Indicators Guidance is available online at:

<http://www.goldstandardsframework.org.uk/TheGSFToolkit/ToolsandTemplates>

Henderson, M. (2010) Where to turn. An Information Guide for Loved ones going into a Care Home. Available to order from www.care2shareni.co.uk Price £5.50

This booklet is one of 3 in the Where 2 Turn series, which offers practical advice and support to carers faced with their loved one's move to a nursing and residential care home. Although it may be most useful during the pre admission phase, it also provides useful insight into the feelings and emotions associated with the transition from home to care home.

NI Reminiscence Network recognises the significance and complexity of Reminiscence and Life Story work and provides a number of training programmes throughout the year. Information about Reminiscence Loan Boxes which can be used to facilitate Reminiscence and Life Story work can be found at: www.rnni.org

Dementia Centre NI website provides valuable information and training resources for supporting people with dementia. Information can be accessed via website www.dementiacentreni.org

National Practice Development Programme (2010) Enhancing Care for Older People. A Guide to Practice Development Processes to Support and Enhance Care in Residential Settings for Older People. Available to download at www.science.ac.uk/inr/public/pdf/Toolkit.pdf

My Home Life website provides a very useful section on the transition form Home into Care Home which can be accessed on www.myhomelife.org.uk/resources

Section 3: Palliative Care Holistic Assessment

3.1 Palliative Care Holistic Assessment

Holistic assessment is a continuous process which should begin if possible prior to admission to the home and remains an integral part of the care provided over the course of the patient journey. It includes assessment of an individual's physical, social, spiritual and psychological needs. This ensures that all the needs of the individual are identified so that a plan of care can be agreed. It allows the individual, those close to them and the care home staff to consider all aspects of care and plan for the future. The holistic assessment should establish, as far as possible, the resident's priorities and treatment to achieve the agreed goals of care.

Key Components of NISAT Core Holistic Assessment²⁷

1. General Background information
2. Life History and Caring Role
3. Physical Health
4. Mental Health and Emotional Wellbeing
5. Awareness and Decision Making
6. Medicines Management
7. Communication and Sensory Functioning
8. Walking and Moving
9. Personal Care and Daily Tasks
10. Living Arrangement and Accommodation
11. Relationships
12. Work Finance and Leisure
13. Quality of life and Future

The guidance in Section 3 is aligned to the following:

Palliative and End of Life Care Competency Framework

- Overarching values and knowledge
- Communication Skills
- Assessment and Care Planning
- Symptom Management, Maintaining Comfort and Wellbeing
- Advance Care Planning

Northern Ireland Single Assessment Tool (NISAT)

Procedural Guidance, Version 3, January 2011 available to download from <http://www.dhsspsni.gov.uk/index/hss/ec-community-care/ec-northern-ireland-single-assessment-tool.htm>

²⁷ Department of Health Social Services and Public Safety (DHSSPS) (2009) *Northern Ireland Single Assessment Tool* available at: <http://www.dhsspsni.gov.uk/index/hss/ec-community-care/ec-northern-ireland-single-assessment-tool.htm>

Assessment of some residents, for example, a person with a learning disability or a person with dementia, often requires staff to work jointly with those who are familiar to and with the person and have prior knowledge of them.

This requires the development of a **therapeutic relationship** between staff, residents and those close to them. This includes excellent communication skills which take account of the personal significance which is being placed on the information being shared by the individual and their family.²⁸

Meeting the needs of the individual and their families also requires effective co-ordination of care across care boundaries. This can only be achieved through effective communication between the various health professionals involved in providing the care.

Key Milestones when Holistic Assessment should be undertaken²⁹

- Admission to the nursing or residential care home
- Identification of the end of life phase – the person could be in the last year / possibly last months or weeks of life⁸
- The point at which dying is diagnosed
- At any other time that the individual may request
- At any other time that a professional carer may judge necessary

Best practice

1. A holistic assessment of the person's needs is completed within 11 days of admission to the nursing or residential care home, as per nursing homes minimum standards. This is reviewed at key points in the individual's care pathway by a key worker who has the appropriate knowledge, skills and competence to carry out the assessment.
2. If possible, the holistic assessment is completed in a single session; however, the key worker is sensitive to the individual's needs and circumstances. Priority needs are identified at an early stage of the assessment.
3. There is a system in place within the home whereby staff can access interpreter services as required to meet the needs of residents who have sensory impairment or those whose first language is not English.

Preparing for the holistic assessment in the home

4. The key worker describes the assessment process to the individual and their family and obtains consent from the person (if appropriate) or a family member.
5. The holistic assessment is undertaken at a mutually agreed pre arranged time so that family members can be present if the individual so wishes.

²⁸ Duke, S & Bailey, C (2008) Communication, Patient and family IN: Payne, S; Seymour, J & Ingleton, C. (Eds) *Palliative Care Nursing. Principles and Evidence for Practice*. 2nd Edition. Maidenhead: Open University Press.

²⁹ National End of Life Care Programme (2010) *Holistic Common Assessment of Supportive and Palliative Care Needs for Adults requiring End of Life Care* available online http://www.endoflifecareforadults.nhs.uk/assets/downloads/HCA_guide.pdf

6. The key worker sets time aside to undertake the holistic assessment and ensures other members of the team are aware of the need to minimise interruptions.
7. The key worker reviews any assessments which were previously undertaken and takes into account any needs identified within them.
8. The key worker is aware that a discussion about holistic needs may lead into conversations about advance care planning. There is a system in place to trigger the process of advance care planning as appropriate.

Following the holistic assessment

9. The key worker, in partnership with the person and their family/carer agree a plan of care including referrals to members of the multidisciplinary team/ specialist palliative care team as appropriate.
10. The identified needs from the holistic assessment act as a trigger to consider advance care planning if this has not already taken place.
11. Assessment information is shared with other members of the care team, the GP and wider multidisciplinary and specialist palliative care teams as appropriate.
12. Information from the holistic assessment and planned interventions from the assessment are clearly recorded in the person's health record.

Useful Tools/Templates

The National End of Life Care Programme website provides a wide range of tools to support holistic assessment which can be downloaded from the Care Pathway section of the website <http://www.endoflifecare.nhs.uk/care-pathway/>

The Palliative Care for People with Learning Disabilities Network (PCPLD) website provides a range of assessment tools and other resources to support assessment of people with learning disabilities. Information can be downloaded from the Link and Resources section of the website <http://www.pcpld.org/links-and-resources/>

Marie Curie Spiritual and Religious Care Competencies for specialist palliative care: accessible at <http://www.mariecurie.org.uk/Documents/HEALTHCARE-PROFESSIONALS/spritual-religious-care-competencies.pdf>

Resources

My Home Life promotes quality of life for those living, dying, visiting and working in care homes, and can be accessed on www.myhomelife.org.uk

The National End of Life Care Programme website provides a wide range of resources to support holistic assessment which can be downloaded from the website <http://www.endoflifecare.nhs.uk>

Examples of guidance available include:

Holistic common assessment of supportive and palliative care needs for adults requiring end of life care (2010) Available online:

http://www.endoflifecareforadults.nhs.uk/assets/downloads/HCA_guide.pdf

Care towards the End of Life for People with Dementia: A Resource Guide. (2010) Available online:

http://www.endoflifecareforadults.nhs.uk/assets/downloads/Dementia_resource_final_20101025.pdf

For evidence based clinical guidelines

Watson, M., Lucas, C., Hoy, A., Back, I. & Armstrong, P. (2011) Palliative Adult Network Guidelines 3rd Edition

Guidelines and Audit Implementation Network, (2011) General Palliative Care Guidelines for the Management of Pain at the End of Life in Adult Patients. GAIN: Belfast. Available online:

www.gain-ni.org/Publications/Guidelines/Gain%20pain%20final.pdf

Section 4: Advance Care Planning

4.1 Advance Care Planning Process

The need to ensure that a person's wishes are respected at the end of their life, even if they are no longer able to communicate those wishes, has become increasingly important over recent years. **Advance Care Planning** informs and empowers individuals to have a say about their current and future wishes and improves end of life care.³⁰ An advance care plan does not override the decision of a competent individual and will only be used in the event that the individual loses **mental capacity**.^{26, 31}

Advance care planning is a voluntary process of discussion between the individual and their professional carers. If the individual wishes, their family and friends may be included in the discussion. It usually takes place when there is anticipation that the individual's clinical condition may decline and result in the loss of mental capacity and/or the ability to communicate effectively.

Advance care planning discussions may lead the individual to make:

- An advance statement or record of wishes
- An advance decision to refuse treatment which may include a do not attempt cardiopulmonary resuscitation decision

An Advance Statement is a written statement either written down by the person or written for them with their agreement. It covers the individual's wishes, preferences, beliefs and values about future care. It may include the type of treatment the person would want or not want, where they would wish to live, or how they wish to be cared for. The advance statement is **Not Legally Binding** but should be taken into account when acting in the person's **best interests**. This can lead on to the legal process associated with an advance decision to refuse treatment.

The guidance in Section 4 is aligned to the following:

Palliative and End of Life Care Competency Framework

- Overarching values and knowledge
- Communication Skills
- Assessment and Care Planning
- Advance Care Planning

Northern Ireland Local Enhanced Services: Advance Care Planning in nursing and Residential Homes

Living Matters, Dying Matters

Palliative and End of Life Care Commissioning Specification

³⁰ Detering, K.M., Hancock, A.D., Reade, M.C. & Silvester, W. (2010) The impact of advance care planning on end of life care in elderly patients: randomized controlled trial. *British Medical Journal* 340:1345 available online: <http://www.bmj.com/content/340/bmj.c1345.abstract?paperoc>

³¹ Royal College of Physicians (2009) Advance Care Planning: National Guideline Concise Guidance to Good Practice 12. London: RCP.

An Advance Decision to Refuse Treatment (also known as Living Will/Advance Directive) is a statement of the person's wish to refuse a particular type of medical treatment or care, in a predefined potential future situation, if they lose sufficient mental capacity).³² In order to be legally binding, an advance decision must be valid and applicable to subsequent circumstances in which the person lacks sufficient mental capacity. An advance decision to refuse treatment is valid if made voluntarily by an appropriately informed person with capacity. Professionals cannot be required to provide particular treatments (which may be clinically inappropriate), however, they should respect an advance refusal of treatment. Failure to do could result in legal action against the practitioner.³³

In order for a **do not attempt cardiopulmonary resuscitation** to be legally binding it must form part of an advance decision to refuse treatment, otherwise it is advisory only and clinical judgement takes precedence.³⁴

New legislation regarding mental capacity is expected soon in Northern Ireland. The guidance below will then be reviewed to reflect any changes within the new legislation.

Best Practice

1. Staff have the appropriate training to enable them to communicate effectively and understand any legal and ethical issues involved in advance care planning.²²
2. Advance care planning discussions are co-ordinated and undertaken jointly by the key worker and the person's usual GP.
3. Staff know who on the team has the knowledge, skills and competence to sensitively and appropriately initiate an advance care plan discussion with residents and their families.
4. Every resident is given the opportunity to develop an advance care plan within three months of admission.⁹ This includes the opportunity to discuss their wishes including their preferred place of care at the end of life.
5. Where the person indicates a wish to undertake advance care planning discussions, they are offered the opportunity to have someone with them during the process.
6. Where the person makes an advance care plan, it is documented. If the person does not wish to discuss future care needs, this is also clearly documented in their health record.
7. With the individual's consent, the key worker informs all members of the team involved in the person's care of any decisions from the advance care plan which

³² Department for Constitutional Affairs (2005) Mental Capacity Act. London: The Stationery Office Limited; 2005 available online: <http://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act>

³³ Department of Health Social Services and Public Safety (DHSSPS) (2003) *Reference Guide to Consent for Examination, Treatment or Care*. Belfast: DHSSPS. available online: <http://www.dhsspsni.gov.uk/consent-referenceguide.pdf>

³⁴ Resuscitation Council (UK) 2010 Resuscitation Guidelines. Available to download at www.resus.org.uk/pages/GL2010.pdf

may impact on that care. This includes any changes made to the advance care plan after review.

8. The GP completes a handover form to advise out of hours and ambulance services which includes decisions from the advance care plan and any advance decision to refuse treatment/do not attempt cardiopulmonary resuscitation status.
9. Where appropriate, the person is included on the palliative care registers held in the home, and GP surgery.
10. The advance care plan is not a static document and is reviewed regularly, either within a timeframe agreed with the individual and those close to them (if they so wish) or as the person's condition changes.
11. In the event that the person lacks capacity or is unable to communicate, the key worker makes reasonable attempts to discover if an advance care plan already exists and ensures this goes with the person if they are being transferred from the home.

4.2 Communication within the Home

Communication between staff in the home is crucial to ensure high quality palliative and end of life care.¹ Regular care review meetings are essential so that all care staff are kept up to date with any changes in the health of individual residents. These meetings give staff in the home an opportunity to discuss the individual's overall condition together and identify those residents with palliative and end of life care needs. This is separate to the annual review meetings which are undertaken with the care manager.

Effective communication with residents, their families, staff within the home, and other health and social care professionals including the GP, allows the person's needs to be identified and anticipated so that early interventions can be put in place and crises reduced.

Care Review Meeting includes:

- Identification of palliative and end of life care needs through review of the individual's overall condition, including any deterioration
- Use of prognostic indicator tools
- Recognition of residents status in terms of stage of illness^{8, 25}

A = Should/ may be years

B = Could be the last year

C = possibly months or weeks

D = probably last few days/hours

Best practice

1. Staff in the home meet regularly to review the overall progress of each resident within the home and plan care holistically. This is in addition to daily handover meetings.
2. Key information from the care review meeting is clearly recorded in the person's notes. This is then used to plan ongoing care.
3. There is a system in place to ensure that any members of staff that were unable to attend the meeting are kept up to date regarding changes in each individual's condition including stage of illness.
4. The key worker communicates with the person's GP and other health and social care professionals involved in the person's care to inform them regarding outcomes of the review meetings. The staff in the home should consider utilising the SBAR communication tool.³⁵

³⁵ SBAR Communication Tool available at:

http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/sbar_-_situation_-_background_-_assessment_-_recommendation.html

4.3 Communication between the Home and the General Practitioner (GP)

All residents in nursing and residential care homes are registered with a GP. There may be a large number of individual GP practices involved with any one home. Good working relationships between staff in the homes and GP practices is essential to ensure the person's healthcare needs are identified and managed in a timely and appropriate manner. This requires a clear understanding of, and respect for, each other's roles in the process of care.

Key points for effective communication between the home and the General Practitioner

- Preparation – know the key facts
- Be clear about what you want and why you want it
- Be clear regarding the agreed plan of management
- Record details of the conversation in the person's notes.

Best Practice

1. Staff in the home have easy access to key contact details for each GP practice and out of hours service in the area. This includes information regarding when and how to contact the surgery for specific reasons, including repeat prescriptions, test results and telephone/visit appointment requests.
2. There is a partnership approach between staff within the home and the GP which is based on mutual respect and understanding of each other's roles.
3. Staff in the home communicate regularly with the person's GP throughout the end of life care phase of care.

4.4 Referral to the Multidisciplinary Team

Multidisciplinary teamwork is identified as a defining characteristic of high quality community based palliative care.³⁶ Whilst the majority of care is provided by staff working in the home, referral to members of the wider multi professional healthcare team is often required to meet the needs of individual residents. In some areas, this requires a referral from the person's GP.

Effective communication with members of the multidisciplinary team is essential in order to build strong working relationships and ensure safe and effective care for residents.¹ Mutual respect and understanding of individual roles are key elements of effective communication within teams.

Best practice

1. There is written information available in each home regarding how to refer to the members of the multidisciplinary team.

³⁶ Forrest, S & Barclay, S. (2007) Palliative care: a task for everyone. *British Journal of General Practice* 57:539 503

2. The key worker assesses the individual holistically and refers to the other members of the multidisciplinary team as required as per local referral guidelines. Referral details are recorded in the person's health record.
3. The key worker updates members of the multidisciplinary team with key information regarding the person, including changes in condition and preferences and wishes as appropriate.
4. The key worker, in partnership with members of the multidisciplinary team jointly assesses residents in the home. This can also mean working jointly across generalist and specialist services with the person and family at the centre.

4.5 Referral to Specialist Palliative Care Services

The vast majority of residents in nursing and residential care homes who have identified palliative and end of life care needs are looked after by staff in the home in partnership with the GP and other members of the multidisciplinary team as required. However, some individuals may benefit from being referred to specialist palliative care services for assessment and management of more complex palliative and end of life care needs. It is important, therefore, that staff within the homes are able to holistically assess the needs of residents and know when to seek advice from, or refer to specialist palliative care services.³⁷

Best practice

1. The key worker in the home, in partnership with the person's GP, identifies complex unresolving palliative care needs and refers the individual to the specialist palliative care team as per local referral guidelines. Referral details are recorded in the person's health record.
2. Staff within the home have close working relationships with members of the specialist palliative care team and there is a named palliative care nurse specialist attached to the home whom staff can contact for advice and support as required.
3. The key worker in the home updates members of the specialist palliative care team with key information regarding the person, including changes in condition and preferences and wishes as appropriate.
4. The key worker in the home works in partnership with members of the specialist palliative care team to jointly assess and manage the individual's palliative and end of life care needs.

4.6 Communication across Care Boundaries

Co-ordinating the care of individuals at the end of life, and that of their families/carers means that integrated services must be provided in a timely and organised way³⁸. Whether the person is being transferred from the home to another care home, being admitted/discharged to/from hospital or simply attending an outpatient appointment, the

³⁷Lansdell J, & Mahoney M. (2011) Developing competencies for end-of-life care in care homes. *International Journal of Palliative Nursing*. 17:3 143-8

³⁸ Department of Health (2008) *End of Life Care Strategy- Promoting High Quality Care for All Adults at the End of Life*. DH. London. Available online: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

effectiveness of communication across care boundaries will have a significant impact on the provision of care.

Best practice

1. Where a directory of local services for older people/people with a learning disability/dementia/palliative care exists, it is easily accessible within each home.

Transfers to the Home/Discharge from hospital

2. Staff should seek key information regarding the planned transfer/discharge prior to admission to the home.
3. This key information should include changes in medication, discussions regarding resuscitation status and advance care plan preferences including preferred place of care.
4. Staff from the home/key worker are available to attend discharge planning meetings for individuals with complex care needs as appropriate.
5. In addition, staff in the home speak directly to the discharging unit in advance of the actual discharge for an update on the person's current health care needs, medications and transfer arrangements to the home.

Transfers from the Home

6. There is a procedure within the home for arranging transport for residents who are attending outpatient appointments/ admission.
7. Regardless of whether the person is being accompanied or not, staff communicate clearly, effectively and in a timely manner with all those who need to be aware of the transfer arrangements, including the individual, their family, and key professionals involved in the person's care. This is clearly documented in the person's health record.
8. A record of all information (written and verbal) which has been sent with the individual is kept in their health record in the home.
9. A list of those professionals involved in the person's care is kept at the front of their health record. If the individual is being transferred for admission to hospital/hospice/another care home or dies, those members of the multidisciplinary team that have been involved in their care are informed by staff in the home/key worker of the transfer. This is then documented within the person's health record.
10. There is regular communication between the home and the unit where the individual is currently an inpatient for a progress report on their condition. Communication processes are in place to ensure the home is aware of any changes in the person's condition or needs, including plans for discharge back to the home.

Following discharge back to the home

11. The person's GP and other members of the multidisciplinary team that have previously been involved in the person's care are informed by the home of the

person's return to the home. This is then documented within the person's health record.

Useful Tools/Templates

Advance Care Planning Discussion template is available online at:

<http://www.goldstandardsframework.org.uk/TheGSFToolkit>

Preferred Priorities of Care template is available online at:

<http://www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare>

Resources

Department of Health Social Services and Public Safety (2003) Reference Guide to Consent for Examination, Treatment or Care. Belfast: DHSSPS. available online:

<http://www.dhsspsni.gov.uk/consent-referenceguide.pdf>

Department of Health Social Services and Public Safety (2003) Good Practice in Consent. Consent for Examination, Treatment or Care. A Handbook for the HPSS. Belfast: DHSSPS. available online: <http://www.dhsspsni.gov.uk/consent-guidepart1.pdf>

The General Medical Council provides guidance on decision making regarding end of life care. Information can be accessed at http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf

Royal College of Physicians (2009) Advance Care Planning. Concise Guidance to Good Practice series. No. 12 London: RCP available to download:

<http://www.rcplondon.ac.uk/sites/default/files/concise-advance-care-planning-2009.pdf>

NHS National End of Life Care Programme website is available at:

<http://www.endoflifecareforadults.nhs.uk>

The website has various factsheets and other information regarding Advance Care Planning including:

- Capacity, care planning and advance care planning in life limiting illness. A Guide for Health and Social Care Staff (2011)
- The differences between general care planning and decisions made in advance
- Advance Care Planning Support Sheet 3 (2010)
- Advance Decisions to Refuse Treatment Support Sheet 4 (2010)
- Decisions made in a person's "best interests"

Some of this information is only valid in England and Wales where the Mental Capacity act applies.

Gold Standards Framework website hosts a large amount of useful information regarding Advance Care Planning which can be accessed at:

<http://www.goldstandardsframework.org.uk>

The website has various factsheets and other information regarding Advance Care Planning including

- Advance Care Planning and Communication Skills
- Advance Care Planning and Do Not Attempt Resuscitation Decisions

The website also hosts GSF Prognostic Indicators Guidance which is available online:

<http://www.goldstandardsframework.org.uk/TheGSFToolkit/ToolsandTemplates>

Useful Tools/Templates

The National End of Life Care Programme provides a number of useful tools and templates to support communication across care boundaries including a sample Directory of Key Contacts which can be accessed via the resources/ routes to success resources section of the website

<http://www.endoflifecare.nhs.uk/search-resources/route-to-success-resources/support-sheets.aspx>

NHS Institute for Innovation and Improvement hosts a number of useful tools including Situation, Background, Assessment, Recommendation - SBAR Communication Tool is a structured method for communicating critical information that requires immediate attention and action contributing to effective escalation and increased patient safety. SBAR can also be used effectively to enhance handovers between shifts or between staff in the same or different clinical areas. It is available for download:

http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/sbar_-_situation_-_background_-_assessment_-_recommendation.html

Section 5: Care at the end of life

5.1 Managing Dying

“The last part of life may have an importance out of all proportion to its length.... . How people die remain in the memories of those who live on”

(Dame Cicely Saunders)

Caring for the dying person and their family requires an active and compassionate approach to care that ensures respect for and dignity of the individual and those that matter to them. Excellent communication between the person, their family and professional carers is essential to ensure high quality end of life care. Regular and systematic assessment of individual and family needs along with anticipation and management of deterioration in the person's condition are fundamental to ensuring those needs are met. The family should be enabled to provide as much care as they wish, kept informed as active members of the team and made feel that everything possible had been done in the care of their dying relative.³⁹

It is very difficult to diagnose when somebody is dying but it may be less difficult to diagnose when somebody *could* have started to die. Regular review meetings between team members will assist in identifying small changes in the individual's condition at an earlier stage and may be helpful when diagnosing when somebody *may* have started to die. Such a diagnosis is best made by the team caring for the individual, in consultation with the GP and other professionals involved in their care.

Such discussions will inform clinical decisions that support the changing goals of care and will assist staff in the delivery of consistent high quality end of life care for residents and their families. A change in the goals of care requires continuous assessment and involves regular reflection, challenge, critical decision-making and clinical skill in the best interest of the person. This should be done jointly by staff in the home, the key worker and the person's GP. A robust continuous teaching and learning programme must be in place to ensure safe and

The guidance in Section 5 is aligned to the following:

Palliative and End of Life Care Competency Framework

- Overarching values and knowledge
- Communication Skills
- Assessment and Care Planning
- Symptom Management, Maintaining Comfort and Wellbeing

³⁹ National Council for Palliative Care (2007) *Focus on commissioning. End of Life Care*. London: NCPCC

effective decision making. The decision to change the goals of care should only be taken by clinicians who are trained, competent and experienced to do so and only after discussion with, and agreement from, the person (if appropriate) and the family.

Diagnosing Dying - Signs and Symptoms of Someone Approaching Death⁴⁰

The National Council for Palliative Care (2006) Guidelines for managing the last days of life in adults advise that the clearest signs of approaching death are picked up by the day to day assessment of deterioration by staff in the home.

- Profound weakness – individual is bedbound and requires assistance with all care
- Diminished intake of food and fluids
- Drowsy or reduced cognition
- Gaunt appearance
- Difficulty swallowing medicines

Best Practice

Diagnosing that a person could be dying prompts the following key actions:

1. Where possible the person is enabled to die in the place of their choice as recorded in their care plan. If staying in the home, the person is cared for in an environment that promotes dignity, respect and privacy.
2. The family is contacted and advised in a sensitive manner that the person's condition has deteriorated. They are kept informed and have opportunities to discuss concerns with the team within the home and the wider team members involved in the care.
3. The GP and other key professionals involved in the individual's care are informed of deterioration in their condition. It is essential that the GP is requested to visit the patient within 28 days prior to death so that they can complete the death certificate.
4. Staff in the home, the GP and other members of the multidisciplinary and specialist palliative care teams work together as appropriate to plan care. The person (if appropriate) and/or their family are involved in the decision making processes.

The plan of care includes:

- all unnecessary medication are discontinued,
 - anticipatory prescribing - subcutaneous medications necessary to manage common end of life symptoms are prescribed on a PRN basis.
5. The person is assessed regularly, including their hydration and nutrition needs, and interventions to promote comfort and dignity are initiated in a timely and responsive manner.

⁴⁰ National Council for Palliative Care (2006) Changing Gear - Guidelines for managing the last days of life in adults. London: NCPC.

6. Staff in the home ensure that the cultural, religious and spiritual needs of the person and their family are identified and met in a sensitive manner through connections with members of the local faith community.
7. When the person is believed to be imminently dying, their family and friends (including other residents) are facilitated as far as possible and in accordance with the person's wishes to spend as much time as they wish with the person. This includes overnight stays if feasible.
8. There is a room or private space available where family members can go to talk privately.
9. The changing goals of care are discussed and agreed with the person (if appropriate) and their family.
10. In the event that family members are unable to be present, the home makes arrangements to ensure a member of staff is deployed to sit with the person, so that they are not left alone while dying. Where this is not possible the home considers accessing other appropriate providers.

Useful Tools/Templates

The National End of Life Care Programme website provides a wide range of resources to support end of life care including *The route to success in end of life care – achieving quality environments for care at end of life*.

These can be downloaded from the Resources/Routes to success section of the website <http://www.endoflifecare.nhs.uk>

Gold Standards Framework website hosts a large amount of useful information regarding End of life Care which can be accessed from the GSF Toolkit section of the website:

<http://www.goldstandardsframework.org.uk/TheGSFToolkit>

Hospice Friendly Hospitals website hosts a number of practical End of Life Care resources which can be accessed on

<http://www.hospicefriendlyhospitals.net/resources-and-courses/>

Palliative Care for People with a Learning Disability Network.

Provides resources in an accessible format for people with learning disabilities.

www.pcpld.org

The General Medical Council provides guidance on decision making regarding end of life care. Information can be accessed at http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf

For evidence based clinical guidelines

Watson, M., Lucas, C., Hoy, A., Back, I. & Armstrong, P. (2011) Palliative Adult Network Guidelines 3rd Edition

Guidelines and Audit Implementation Network, (2011) General Palliative Care Guidelines for the Management of Pain at the End of Life in Adult Patients GAIN: Belfast. available online:

www.gain-ni.org/Publications/Guidelines/Gain%20pain%20final.pdf

Section 6: Care after Death

6.1 Care after Death

Care after death is an important part of caring for the person holistically. It includes personal care after death, (previously known as 'last offices'), and ongoing support of the family and carers.⁴¹ This is a very difficult time for those who have been bereaved and requires sensitive and skilled communication in order to ensure their needs are met, whilst also respecting the integrity of the person who has died.

The person's death does not only affect their family. Other residents in the home may be very sad or even quite distressed by the death, and will also need to be supported by staff and have their bereavement acknowledged. They should be given the choice and opportunity to engage in death rituals such as attending the funeral if that is what they wish to do. Care after death can also be emotionally challenging for staff and requires a sensitive and supportive approach from other colleagues.

Whilst care after death is the final act of care, it is the first stage of a pathway that involves a range of professional groups. Effective communication between the professionals and across organisations is vital if the process is to run smoothly

Best practice

1. The home has a procedure that guides the care, privacy and dignity of the deceased person during the last offices of care at the time death.
2. The spiritual and cultural wishes of the deceased person and their family are respected and as far as possible, facilitated; whilst ensuring legal obligations are met.
3. The time the person dies is recorded in the person's health record.
4. Verification of death is completed as per the policy within the home.

The guidance in Section 6 is aligned to the following:

Palliative and End of Life Care Competency Framework

- Overarching Values and Knowledge
- Communication Skills
- Advance Care Planning
- Assessment and Care Planning

Living Matters, Dying Matters

⁴¹ National Nurse Consultant Group (2011) Guidance for staff responsible for care after death (last offices) NNCG. Available at: http://www.endoflifecareforadults.nhs.uk/assets/downloads/Care_After_Death_final_draft_20110610.pdf

5. The home has a local agreement with GP's regarding the timely completion of the death certificate.
6. Where the family has not been able to be present at the death, they are informed in a sensitive manner that the person has died. This should be inclusive of family members with a learning disability. A record is made of who has been informed.
7. The family is enabled to spend time with the deceased person after death.
8. There is a room or quiet private space available for family members after death.
9. Other residents in the home are informed in a sensitive manner that the person has died and those residents who wish to pay their respects to the deceased person are enabled to do so.
10. There is clear and effective communication between staff in the home and funeral director to ensure the smooth and dignified transfer of the deceased person to the funeral director premises.
11. The family is offered the opportunity to participate in the personal care after death of the deceased person. If they wish to participate, they are supported to do so in a sensitive manner by staff who have the knowledge and skills to undertake the process.
12. The deceased person's personal effects are returned to the family in a dignified manner using an appropriate handover bag or case. This is documented as per the policy within the home.
13. There are processes in place to protect the health and safety of everyone who is involved in the personal care after death of the person.
14. There is written information available within the home to assist families regarding practical and legal requirements when a person dies. This includes information regarding bereavement support services.
15. All professionals involved in the person's care are informed of the person's death in a timely manner. This is recorded in the person's health record.

6.2 Bereavement Care

Experiencing the loss of someone close through death is an inevitable part of life but that does not make it easy, even when the death is expected. It is estimated that for every death, at least four relatives and friends feel the loss. Memories of the death and of the person who has died can be affected by the perception of the quality of the end of life care provided to them. These can significantly influence grieving and the longer term health of the bereaved person.⁴² A holistic, co-ordinated approach to bereavement care is therefore needed and applies during the whole 'journey' of bereavement i.e. prior to, at the time of, and following the death.⁴³

The regional strategy for bereavement care for Northern Ireland⁴² has identified six standards around key themes to assist Health and Social Care services in the delivery of care and support to people who are dying and their families, friends and carers and for those services coming into contact with them at other times. The following standards were identified:

- 1. Raising awareness:** That Health and Social Care staff will be suitably trained to have an awareness and understanding of death, dying and bereavement. Staff should also acknowledge the fact that grief is a normal process following loss, and that needs vary according to an individual's background, community, beliefs, and abilities.
- 2. Promoting safe and effective care:** That all Health and Social Care staff who have contact with people who are dying and/or with those affected by bereavement will deliver high quality, safe, sensitive and effective care before, at the time of and after death according to individuals' backgrounds, communities, beliefs and abilities.
- 3. Communication, information and resources:** That people who are dying and those who are affected by bereavement will have access to up-to-date, timely, accurate and consistent information in a format and language which is appropriate and will be helpful to their particular circumstances consistent with their needs, abilities and preferences. Staff will remember that the availability of written or other information does not negate their personal support role.
- 4. Creating a supportive experience:** That those who are dying and their families will be afforded time, privacy, dignity and respect and, wherever possible, given the opportunity to die in their preferred environment with access to practical, emotional and spiritual support based on their individual needs, abilities and preferences.
- 5. Knowledge and skills:** That Health and Social Care organisations recognise the value of a skilled workforce by ensuring that those coming into contact with, or caring for people who are dying and those affected by bereavement are competent to deliver care through continuing professional development; and by having systems in place to support them.
- 6. Working together:** That good communication and co-ordination will take place within and between individuals, organisations and sectors, to ensure that resources are targeted

⁴² . Department of Health (2005) *When a Patient Dies. Advice on Developing Bereavement Services* available online at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4122193.pdf

⁴³Department of Health Social Services and Public Safety (DHSSPS) (2009) *Northern Ireland Health and Social Care Services Strategy for Bereavement Care* available online at www.dhsspsni.gov.uk

efficiently and effectively and that there is integration of care to meet the needs of people who are dying and their families, friends and carers.

Bereavement care should be extended to all persons affected including residents, relatives, friends and staff, across all aspects of diversity (i.e. religious belief, political opinion, race, age, marital status, sexual orientation, gender, disability, carers, social, economic, rural and urban needs)⁴⁴ and regardless of circumstances of the death. Bereavement care is not simply the domain of specialist bereavement services alone but in fact needs to be considered as part of the role of all health and social care professionals.

Best Practice

Pre bereavement care

1. Accurate, timely, clear and detailed information is offered to individuals, their families and carers to ensure that informed choices can be made and they are continuously included in the care planning process as partners.
2. Staff are sensitive to the different information needs within families/carer and residents groups and they are prepared for the person's death as far as possible.
3. Information regarding local spiritual and religious services is available within the home.
4. The religious and spiritual beliefs and the cultural background of the individual and their family are respected. Additional support from clergy and other spiritual and religious services is accessed as required to meet individual needs.
5. The home has systems in place for referral for ongoing pre bereavement support as appropriate.

Post bereavement care

6. Written information regarding the practical and emotional aspects of bereavement is available in a variety of formats that meets the needs of bereaved individuals including those that have a learning disability, sensory or cognitive impairments and those whose first language is not English. The information available is sensitive and relevant to different faiths and cultures as appropriate to meet the needs of the individual family and carer groups.
7. There are supportive systems in place to identify and meet the bereavement needs of residents and staff in the home.
8. There is a system in place to engage with families enabling them to provide feedback regarding their experiences of care received in the home.

⁴⁴ Section 75 of the Northern Ireland Act 1998

Useful Tools/Templates

The National End of Life Care Programme provides support sheets including a sample Directory of Key Contacts which can be accessed via the resources/ routes to success resources section of the website

<http://www.endoflifecare.nhs.uk/search-resources/route-to-success-resources/support-sheets.aspx>

Help the Hospices website hosts information on bereavement including guidance regarding bereavement risk assessment which can be accessed from:

<http://www.helpthehospices.org.uk/our-services/developing-practice/bereavement/?locale=en>

Resources

Department of Health and Social Services and Public Safety (2009) Northern Ireland Health and Social Care Services Strategy for Bereavement Care Belfast: DHSSPS

<http://www.dhsspsni.gov.uk/nihsc-strategy-for-bereavement-care-june-2009.pdf>

Guidance for staff responsible for care after death (last offices) Developed by National End of Life Care Programme and National Nurse Consultant Group (Palliative Care)

http://www.endoflifecareforadults.nhs.uk/assets/downloads/Care_After_Death_guidance.pdf

For useful information available regarding what to do after the person dies go to:

<http://www.direct.gov.uk/en/Governmentcitizensandrights/Death/WhatToDoAfterADeath/index.htm>

The Hospice Friendly Hospitals website has a number of useful resources including practical end of life care resources

- End of Life Symbol which can be displayed at the nurses' station or at the ward/unit entrance to notify staff that a patient has died. It can be downloaded free and placed in own frame.
- The Family Handover Bag: The principle of the family handover bag is to promote a dignified and sensitive way of returning the deceased patient's personal belongings to the family. A high quality bag should be used in place of a plastic bag.

Hospice Friendly Hospitals (2011) Competence and Compassion Map for End of Life Care: Information regarding the development of a bereavement policy and understanding grief in the workplace

A wide range of bereavement information leaflets are also available from the website:

http://www.hospicefriendlyhospitals.net/resources-and_courses/itemlist/category/17-resources-general/

Gold Standard Framework has developed the *After Death Analysis* Audit Tool. This online audit looks at actual care given to patients from the perspective of the practice or care home. The tool itself can only be downloaded by registered users of the GSF programme, however, there is very useful information regarding the audit tool freely accessible via the website: <http://www.goldstandardsframework.org.uk/GSFAuditTool>

The National End of Life Care Programme website provides a wide range of resources regarding bereavement care including *When a Person Dies, guidance for professionals*

http://www.endoflifecareforadults.nhs.uk/assets/downloads/When_a_Person_Dies_19_Oct_2011_web.pdf

Useful information regarding local bereavement services is available on Health and Social Care Trust websites. These are listed under 7.4 Organisations and Websites

Section 7: Support, Training and Development

7.1 Support for Staff

An essential element of good care within the homes includes support for staff. This should be developed through robust training and development programmes and staff support systems. It is important that staff recognise the impact of caring at the end of life within their own life, and support each other both professionally and personally in this important aspect of their work. This also means staff having self awareness about their own feelings and attitudes towards death and dying and the impact of their own personal losses which can make working with people who are dying difficult.

Best Practice

1. Staff support services relating to end of life care reflect the need for both peer support and professional support systems.
2. The home provides opportunities for staff to engage in reflective practice, debriefing after death and clinical supervision.⁴⁵

7.2 Education and Training

The delivery of high quality palliative and end of life care is dependent on having a compassionate, skilled knowledgeable and competent workforce.¹ This requires access to education and training opportunities in end of life care, in accordance with individual roles and responsibilities.

Based on the Palliative and End of Life Care Competency Assessment Tool,⁷ palliative and end of life care education and training should include:

- The ethos, philosophy and principles of palliative and end of life care
- Principles of holistic assessment
- Communication skills
- Care of the family pre and post bereavement
- Self care
- Role of the key worker
- Advance care planning
- Identifying and diagnosing the deteriorating and dying person
- Managing common symptoms at end of life
- Decision making around changing the goals of care
- Management of a syringe driver

Best Practice

1. Nursing and residential homes ensure staff have access to and are supported to attend/undertake evidence based training and development opportunities designed to ensure they are competent and compassionate in delivering palliative and end of life care within the remit of their individual roles and responsibilities. These include practice development processes which enable reflective experiential learning.

⁴⁵ Chief Nursing Officer for Northern Ireland (2007) Standards for Supervision for Nursing. Belfast: DHSSPS

2. All new staff receive training on the general principles and components of palliative and end of life care as part of initial induction to the home.
3. The learning and development needs of staff are assessed according to their roles in delivering palliative and end of life care, and take account of regional and nationally agreed competencies and standards.

7.3 Further Reading

Department of Health, Social Services and Public Safety (2011) *Improving Dementia Services in Northern Ireland: A Regional Strategy* DHSSPSNI: Belfast

Guidelines for Audit and Implementation Network (2010) *Caring for People with Learning Disability in General Hospital Settings*. GAIN: Belfast

Available online at:

<http://www.gain-ni.org/Publications/Guidelines/Gain%20disability.pdf>

National Council for Palliative Care (2011) *Difficult Conversations: Making it easier to talk to people with dementia about end of life care* NCPC www.ncpc.org.uk

National End-of-Life Care Programme (2010) *The route to success in end-of-life care - achieving quality in care homes* www.endoflifecareforadults.nhs.uk

National End-of-Life Care Programme (2011) *The route to success in end-of-life care - achieving quality for people with learning disabilities*. www.endoflifecareforadults.nhs.uk

7.4 Organisations and Websites

All Ireland Institute for Hospice and Palliative Care (AIHPC)

www.aiihpc.org

Alzheimers Association

www.alz.org

Alzheimer's Society

www.alzheimers.org.uk

Belfast Health and Social Care Trust

www.belfasttrust.hscni.net

Easy Health

A website which provides accessible information about health issues for people with learning disabilities.

www.easyhealth.org.uk

Foyle Hospice

www.foylehospice.com

General Medical Council

www.gmc-uk.org

Macmillan Cancer Support

Website provides useful information for patients and families about cancer including booklets and other resources

Learn Zone section has useful e learning resources for Health and Social Care Staff

www.macmillan.org.uk

Marie Curie Cancer Care

www.mariecurie.org.uk

Northern Health and Social Care Trust

www.northerntrust.hscni.net

Northern Ireland Hospice

Northern Ireland Hospice Education and Research Department offers a range of education and training courses in palliative and end of life care. Information can be accessed online:

www.nihospice.org

Nursing and Midwifery Council

<http://www.nmc-uk.org/>

National Council for Palliative Care

www.ncpc.org.uk

Palliative Care for People with a Learning Disability Network (PCPLD)

Provides resources in an accessible format for people with learning disabilities.

www.pcpld.org

Public Health Agency

www.publichealth.hscni.net

Royal College of Nursing

www.rcn.org.uk

Social Care Institute for Excellence

www.scie.org.uk

South Eastern Health and Social Care Trust

www.setrust.hscni.net

Southern Area Hospice Services

www.southernareahospiceservices.org

Southern Health and Social Care Trust

www.southerntrust.hscni.net

Western Health and Social Care Trust

www.westerntrust.hscni.net

7.5 Further Resources

Local Practice Development Initiative

Curry, C, Middleton, H and Brown B (2009) Palliative Care Training. *Nursing Older People*. Vol.21. No.9 pp18-23.

This article describes a local initiative, delivering palliative care education using a practice development framework, and based on the Macmillan Pack (Katz et al, (2004), above) and reports on successful and sustained outcomes. Project has since been repeated in other nursing homes in the South Eastern Health and Social Care Trust area of Northern Ireland.

Hospice Friendly Hospitals

The Hospice Friendly Hospitals website has a number of useful end of life care resources which can be downloaded from

<http://www.hospicefriendlyhospitals.net/resources-and-courses/itemlist/category/17-resources-general>

The Institute of Nursing and Health Research Person Centred Practice, University of Ulster website hosts valuable resources and publications regarding person centred care. It's excellent resources are available online at: www.science.ac.uk/inr/pcp.php

National End of Life Care Programme

Route to Success Resources

The aim of the Route to Success series is to provide the staff with a simple guide to support the implementation of the end of life pathway. Additional helpful resources can be accessed via the Resources/Routes to success section of the website:

<http://www.endoflifecare.nhs.uk/search-resources/route-to-success-resources.aspx> last accessed 8-3-13

Northern Ireland Practice and Education Council (NIPEC)

Website hosts a large number of excellent practical resources for health professionals to facilitate personal and professional development. Information can be found on: www.nipec.hscni.net/res_rolesguide.htm and

www.nipec.hscni.net/webinar/learningneedsanalysis/player.html

Last accessed 8-3-13

Resources for People with Learning Disability

'Books Beyond Words' a series of picture books focusing on a number of health issues including palliative and end-of-life care www.rcpsych.ac.uk/publications/bbw

Blackman, N and Brooks, M (2008) *Dementia and people with learning disabilities: Valuing relationships. Training pack* (DVD/Cards) available from Respond by email: admin@respond.org.uk

Read S & Morris H (2009) *Living and Dying with Dignity – the best practice guide to end of life care for people with a learning disability*. Available online:

www.mencap.org.uk/sites/default/files/documents/2009-04/best_practice_guide.pdf

DisDat Tool

A tool developed by staff of St. Oswald's Hospice to assess distress in people who are cognitively impaired www.mencap.org.uk/resources

The Hospital Communication Book provides a range of information about healthcare in an accessible format for people with learning disabilities. Available to download at: www.mencap.org.uk

National End of Life Care Programme / NHS North East (2007)

End of Life Care: A Resource Pack for those caring for or supporting people with a learning disability at the end of life. *What can we do?: A guide to offering care and support to people with a learning disability at the end of life*

http://www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_eolc_learning_disability_res_pack.pdf last accessed 8-3-13

Glossary of Terms

Advance Care Planning

The process whereby a individual, in consultation with relevant staff and appropriate carers, discusses his/her future health and social care wishes, values and preferences. It seeks to create a record of these discussions which can be used to inform future care.

Advance Decisions to Refuse Treatment (ADRT)

Previously known as a living will or advance directive, this is a decision that can be made in order to refuse a specific medical treatment in whatever circumstances that are stated. This can include the choice to refuse treatment even if doing so might put an individual's life at risk. The ADRT will not be used if an individual can make their own choices at the time that the treatment is needed and offered.

Advance Statements

These are written statements (either written down by the person themselves or written down for them with their agreement) the person might make before losing capacity about their wishes and feelings regarding issues they wish to be considered in the case of future loss of capacity due to illness, such as the type of medical treatment they would want or not want, where they would prefer to live or how they wish to be cared for. Advance statements should be used to help find out what somebody's wishes and feelings might be, as part of working out their best interests when they have lost capacity to decide. They are not the same as advance decisions to refuse treatment and are not binding.

Best interests decision

Everything that is done for or on behalf of a person who lacks capacity must be in that person's best interests. An individual's best interests are not limited to their medical best interests. Other factors which form part of the best interests decision include:

- the wishes and beliefs of the patient when competent
- their current wishes
- their general well-being
- their spiritual and religious welfare

Mental Capacity

Refers to the ability of an individual to make a decision about a particular issue at the time the decision needs to be made or to give consent to a particular act.

Do Not Attempt Cardiopulmonary Resuscitation

A written order from a doctor that resuscitation should not be attempted in the event of a person suffering cardiac or respiratory arrest. Such an order may be considered appropriate in cases where successful restoration of the circulation is likely to be followed by a quality of life that would be unacceptable to the patient, or when cardiac or respiratory arrest is the end result of a disease process in which appropriate treatment options have been exhausted.

High complexity of palliative care needs

Palliative care needs that cannot be addressed through simple or routine methods or care and require referral to specialist services.

End of Life

This is the period of time during which an individual's condition deteriorates to the point where death is either probable or would not be an unexpected event within the ensuing 12 months, however, a specific timescale cannot always be applied.¹ The ELCOS (Appendix 2)⁸ emphasises that acute and palliative care can take place at the same time, where it is only possible to predict that the person could possibly be in the last year of life.

End of Life Care

This helps all those with advanced, progressive, incurable conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both the person and the family to be identified and met through the last phase of life and into bereavement. It includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support.⁴⁶

Enduring Power of Attorney

In Northern Ireland, an enduring power of attorney can be appointed to enable an individual, while they are still mentally capable, to nominate someone to deal with their property and financial affairs for them, after they become mentally incapable. In England and Wales, an additional **Lasting Power of Attorney** exists which allows an individual to appoint someone to make decisions about their welfare also.

General Palliative Care

This is provided by the usual professional carers of the patient and family with low to moderate complexity of palliative care needs. Health and social care professionals providing this day to day care should be able to:

- assess the care needs of each patient and their families across the domains of physical, psychological, social spiritual and information needs,
- meet those needs within the limits of their knowledge, skills, competence in palliative care,
- know when to seek advice from or refer to specialist palliative care services.⁴⁷

Mental Capacity Act (MCA)

The Mental Capacity Act 2005 (England and Wales only) provides a statutory framework to empower and protect vulnerable people who are not able to make their own decisions. It makes it clear who can take decisions, in which situations, and how they should go about this. It enables people to plan ahead for a time when they may lose capacity.

Multidisciplinary

A multidisciplinary team is a group of professionals from different disciplines who work together to provide or to improve care for people with particular needs. The members of such a team will vary according to circumstances, but will normally include both healthcare and non-healthcare representatives.

⁴⁶ National Council of Palliative Care (2007) *End of Life Care – A Commissioning Perspective*. London: NCPC

⁴⁷ National Council for Palliative Care. *Palliative Care Explained*. Available online: www.ncpc.org.uk/site/professionals/explained

Nursing homes provide nursing care for people suffering from any illness or infirmity.

Palliative Care is defined as ‘the active, holistic care of patients with advanced **progressive illness**. Management of pain and other symptoms and provision of psychological, social, and spiritual support is paramount. The goal of care is to achieve the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments’.⁴⁸

Palliative care register

A method of recording and reviewing individuals who have been identified as potentially nearing the end of their life, particularly those in the last year of life. It is intended to ensure that any individual has the opportunity for appropriate palliative and end of life care regardless of their condition or care setting. It acts as both a register of patients and as an aide memoir for those involved in their care by assisting early planning for the end of life; assisting recognition of wishes and preferences towards the end of life; assisting access to appropriate palliative and supportive care regardless of condition or care setting; act as an aide memoir for staff members who care for and support patients and families towards the end of life.

Prognosis

The expected progression of a disease and its outcome for the individual

Progressive illnesses

Conditions which result in progressive deterioration and loss of function. Examples include some heart and lung diseases and neurological conditions such as dementia.

Quality of life

Term used to describe the overall assessment of a person’s situation and their sense of personal well-being.

Residential care homes provide residential accommodation with both board and personal care for persons in need of personal care by reason of old age and infirmity; disablement; past or present dependence on alcohol or drugs; or past or present mental disorder.

Specialist Palliative Care

This is provided for individuals and their families with moderate to **high complexity of palliative care needs**. The core service components are provided by a range of NHS, voluntary, and independent providers, staffed by a **multidisciplinary team** whose core work is palliative care.¹²

Therapeutic relationship

This is the relationship which is built on honesty, integrity, and genuineness between the person/ family and the health and social care professional.

World Health Organisation: Principles of Palliative Care⁴⁹

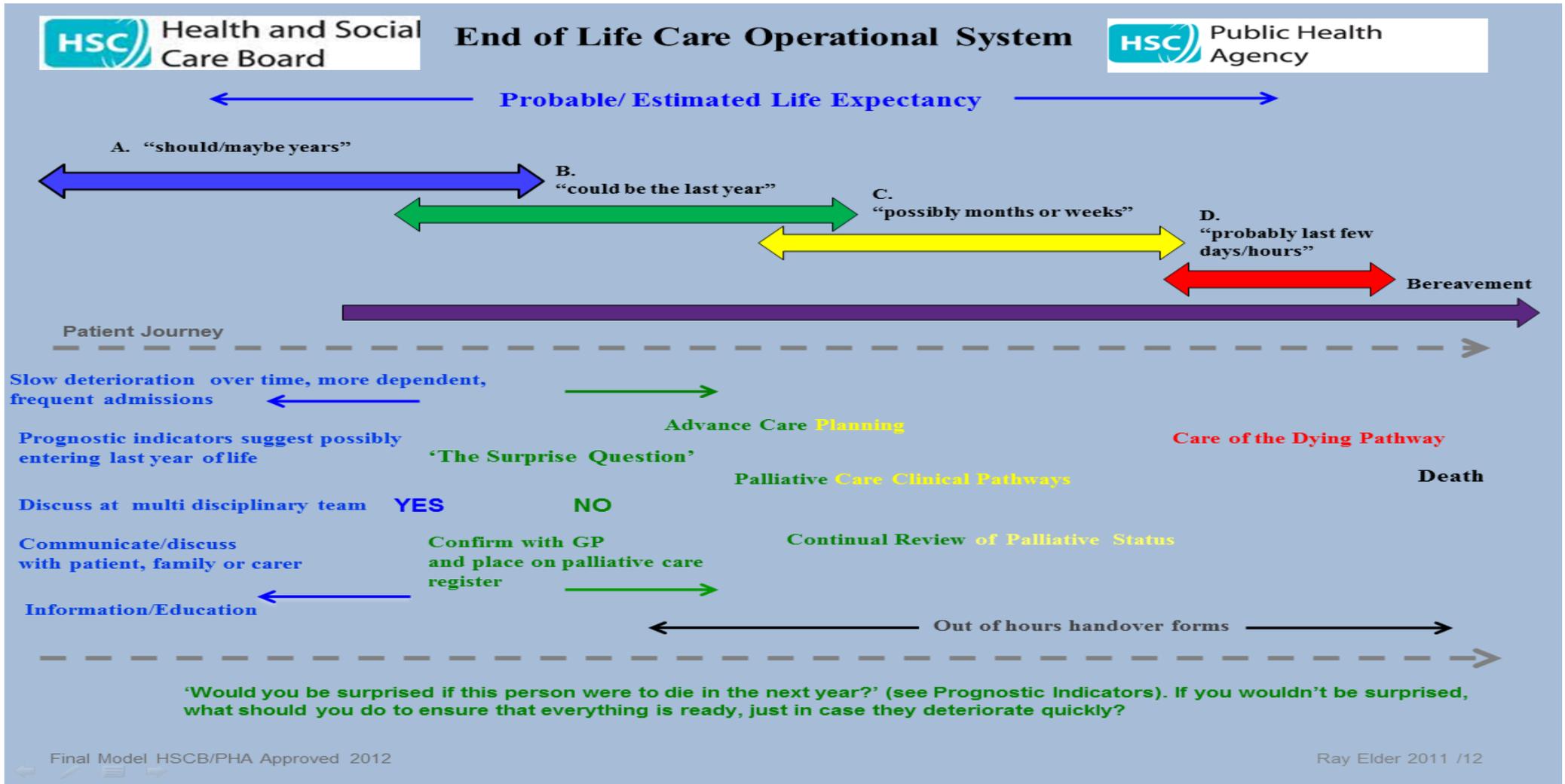
The principles of palliative care reflect a palliative care approach to care and may be applicable from initial diagnosis.

⁴⁸ National Council for Hospice and Specialist Palliative Care Services (2004) The House of Commons Health Committee into Palliative Care. London: NCHSPCS. Available online: <http://www.ncpc.org.uk/palliative-care-explained>

⁴⁹ World Health Organisation *Definition of Palliative Care*. Geneva: WHO <http://www.who.int/cancer/palliative/definition/en/>

This approach:

- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- provides relief from pain and other distressing symptoms;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death irrespective of diagnosis, gender, cultural, religious and spiritual orientation;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance **quality of life**, and may also positively influence the course of illness.



ELCOS End of Life Care Operational System: Triggers for Action



Triggers for Action

Name:

D.O.B:

Should / may be years A	Could be last year B	Possibly months or weeks C	Probably last few days or hours D	First Days after Death and Bereavement
Holistic Assessment <input type="checkbox"/> Medical & Nursing Care Plan completed <input type="checkbox"/> Key worker nominated <input type="checkbox"/> (see <i>Keyworker Guidance</i>)	Holistic Assessment <input type="checkbox"/> Medical & Nursing Care Plan completed <input type="checkbox"/> Key worker nominated <input type="checkbox"/> (see <i>Keyworker Guidance</i>)	Holistic Assessment <input type="checkbox"/> Medical & Nursing Care Plan completed <input type="checkbox"/> Symptom management <input type="checkbox"/> Key worker nominated <input type="checkbox"/> (see <i>Keyworker Guidance</i>)	Holistic Assessment <input type="checkbox"/> Medical & Nursing Care Plan completed <input type="checkbox"/> Symptom management <input type="checkbox"/> Key worker nominated <input type="checkbox"/> (see <i>Keyworker Guidance</i>)	Verification of death <input type="checkbox"/> Care of the Dying Plan completed <input type="checkbox"/> Certification of death <input type="checkbox"/> Key worker nominated <input type="checkbox"/> (see <i>Keyworker Guidance</i>)
Advance Care Planning: Offered <input type="checkbox"/> Completed <input type="checkbox"/> Declined <input type="checkbox"/>	Advance Care Planning: Offered <input type="checkbox"/> Completed <input type="checkbox"/> Reviewed <input type="checkbox"/> Declined <input type="checkbox"/>	Advance Care Planning: Offered <input type="checkbox"/> Completed <input type="checkbox"/> Reviewed <input type="checkbox"/> Declined <input type="checkbox"/>	Advance Care Planning: Offered <input type="checkbox"/> Completed <input type="checkbox"/> Reviewed <input type="checkbox"/> Declined <input type="checkbox"/>	Bereavement support offered to Relatives <input type="checkbox"/> Staff <input type="checkbox"/> Other residents <input type="checkbox"/>
Prognostic indicators suggest possibly entering last year <input type="checkbox"/> (see <i>Prognostic Indicator Guidance</i>)	Patient identified and added to GP Register <input type="checkbox"/> Care Homes Register <input type="checkbox"/>	GP register updated <input type="checkbox"/> Care Home updated <input type="checkbox"/>	Multidisciplinary Team, patient and family agree decision to commence Care of the Dying Plan. <input type="checkbox"/>	Signpost relative to bereavement counselling services if necessary <input type="checkbox"/>
Decisions agreed and communicated to patient and relatives/carers. Needs reviewed <input type="checkbox"/> Needs addressed <input type="checkbox"/>	Decisions agreed and communicated to patient and relatives/carers. Needs reviewed <input type="checkbox"/> Needs addressed <input type="checkbox"/>	Decisions agreed and communicated to patient and relatives/carers. Needs reviewed <input type="checkbox"/> Needs addressed <input type="checkbox"/>	Decisions agreed and communicated to patient and relatives/carers. Needs reviewed <input type="checkbox"/> Needs addressed <input type="checkbox"/>	Decisions agreed and communicated to relatives/carers. Needs reviewed <input type="checkbox"/> Needs addressed <input type="checkbox"/>
Appropriate leaflets given to patients & family <input type="checkbox"/>	Appropriate leaflets given to patients & family <input type="checkbox"/>	Appropriate leaflets given to patients & family <input type="checkbox"/>	Appropriate leaflets given to patients & family <input type="checkbox"/>	Offer bereavement leaflet <input type="checkbox"/>

Should / may be years A	Could be last year B	Possibly months or weeks C	Probably last few days or hours D	First Days after Death and Bereavement
Equipment assessment Needs reviewed <input type="checkbox"/> Needs addressed <input type="checkbox"/>	Equipment assessment Needs reviewed <input type="checkbox"/> Needs addressed <input type="checkbox"/>	Equipment assessment Needs reviewed <input type="checkbox"/> Needs addressed <input type="checkbox"/>	Equipment assessment Needs reviewed <input type="checkbox"/> Needs addressed <input type="checkbox"/>	Ensure all equipment is collected <input type="checkbox"/> Advise family on safe disposal/ return of medication <input type="checkbox"/>
		Request assessment: GP <input type="checkbox"/> DN <input type="checkbox"/> Other <input type="checkbox"/>	GP assessment requested <input type="checkbox"/>	Notify all health and social care professionals involved in the care of the patient <input type="checkbox"/> Ambulance Service updated <input type="checkbox"/>
		DNAR-CPR status considered, documented and communicated. <input type="checkbox"/> Ambulance service updated <input type="checkbox"/>	Symptoms addressed and actioned as per Care of the Dying Plan/ local medication guidelines <input type="checkbox"/>	Significant Event Analysis. Complete post death information audit form <input type="checkbox"/>
		Update: GP OOH service <input type="checkbox"/> District Nurses <input type="checkbox"/>	Update: GP OOH service <input type="checkbox"/> District Nurses <input type="checkbox"/>	
		Review targets, medication and therapies discontinue non-essential medications when appropriate <input type="checkbox"/>	Review targets, medication and therapies discontinue non-essential medications when appropriate <input type="checkbox"/>	
		Anticipatory prescribing considered. <input type="checkbox"/> Actioned <input type="checkbox"/> Obtain/ source Syringe Driver <input type="checkbox"/>	Anticipatory prescribing considered. <input type="checkbox"/> Actioned <input type="checkbox"/>	

1. GAIN Palliative Care Self Assessment for Nursing & Residential Homes 2014

This self assessment has been designed to support and complement the GAIN Guidelines for Palliative and End of Life Care in Nursing and Residential Homes.

The self assessment has been adapted from The NHS National End Of Life website and is based on the NW of England and their training programme "Six Steps to Success programme for care homes"

1. Contact details for Nursing or Residential Home

Name of Home	<input type="text"/>
Address 1	<input type="text"/>
Address 2	<input type="text"/>
Address 3	<input type="text"/>
Post Code	<input type="text"/>
Name contact completing self assessment	<input type="text"/>
Contact telephone	<input type="text"/>
Contact email	<input type="text"/>

It consists of 15 questions divided into 6 parts or sections.

Part 1: Discussions as the end of life approaches

Part 2: Assessment, care planning and review

Part 3: Co-ordination of care

Part 4: Delivery of high quality care in care homes

Part 5: Care in the last days of life

Part 6: Care after death

The self assessment should identify the strength and weakness of the care provided and help identify areas for further improvement.

Homes should identify at least 3 areas for improvement following the assessment.

Homes should refer to the GAIN guidelines for more details.

2. Completion notes

To assess the quality of end of life care within your care home, please complete all of the following questions according to the scoring criteria given below.

All questions need to be completed and the programme will not allow you to move to the next page. You may however go back and edit a previous entry.

Use the checkboxes next to each question to record your judgements. For each statement, please select just one score.

Scoring criteria:

0 - No - nothing in place

1 - Yes - something in place

2 - Yes - something in place and recorded in the care plan

3 - Yes - something in place with another form of written evidence

3. Part 1: Discussions as the end of life approaches

Not all residents are in the last year of life. The first step is about identifying residents who are thought to be in their last year of life so that discussions around the end of life care and advance care planning can be initiated.

***2. Where possible those who are approaching end of life are identified and their information is recorded by some method.**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

***3. There is a system in place that enables families and carers to be involved in end of life decisions if the residents wish.**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

4. Part 2: Assessment, care planning and review

This is about the early assessment of a resident's needs and wishes as they approach the last year of life. The aim is to establish their preferences and choices as well as identify areas of unmet need. It is important to explore the physical, psychological, social, spiritual, cultural and environmental needs and wishes of each resident.

***4. Residents are given the opportunity to express their personal wishes and preferences in relation to future care.**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

***5. An assessment of end of life care needs is carried out in partnership with residents. This includes social, psychological and spiritual as well as physical needs.**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

***6. Residents' needs for end of life care are assessed and reviewed on an ongoing basis.**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

5. Part 3: Co-ordination of care

This is about co-ordinating services. Once a care plan has been agreed it is important that all the services required are effectively co-ordinated. A lack of co-ordination can mean a resident's needs and preferences are not met.

***7. There is in place a method for communication both internally and with external organisations.**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

***8. A key worker is identified and linked to each resident who is approaching end of life.**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

***9. Systems are in place for timely access to any equipment or drugs which may be necessary for the delivery of end of life care, including weekends and out of hours**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

6. Part 4: Delivery of high quality care in care homes

Residents and their families may need access to a complex combination of services across a number of different settings. This is about the delivery of high quality care and the expectation that residents should receive the same level of care regardless of whether they live independently at home or in a care home.

***10. All staff can access end of life care training and support appropriate to their role, to ensure they have the right level of knowledge and skills necessary to deliver good end of life care.**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

***11. The home has the right environment and equipment available to support residents and relatives during end of life care and provide privacy, dignity and respect e.g. quiet rooms, overnight facilities for relatives.**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

***12. There are systems in place to evaluate and monitor the quality of the end of life care service delivery.**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

7. Part 5: Care in the last days of life

The point comes when the resident enters the dying phase. It is vital that staff recognise the person is dying and take appropriate action. How the person dies remains a lasting memory for relatives, friends, and care staff involved.

***13. A validated integrated care plan is available for use during the last few days of life.**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

***14. The home has procedures to ensure that where possible residents' stated wishes and preferences for the last days of life are adhered to, and anticipates and prepares for any specific religious, spiritual or cultural needs they might require.**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

8. Part 6: Care after death

Good end of life care does not stop at the point of death. The support and care provided for relatives will help them cope with their loss and is essential for achieving a "good death". It is also important for staff, many of whom will become emotionally connected to the resident.

***15. Relevant and supporting information is provided for relatives during the last days of life and after death.**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

***16. Staff and other residents are provided with the opportunity to share their feelings and pay respect after a resident dies.**

- 0 - No – nothing in place
- 1 - Yes – something in place
- 2 - Yes – something in place and recorded in the care plan
- 3 - Yes – something in place with another form of written evidence

9. Action plan following self assessment

Nursing and Residential homes should have a realistic action plan to address needs identified from the self assessment.

***17. Has the home developed an action plan**

- No - thinking about
- Yes - work in progress
- Yes - completed
- No plans to undertake this section

*** 18. Identify 3 areas for improvement that the home plans to work on over the next 12 months**

10. Details of the home

*** 19. Name of Nursing or Residential Home**

*** 20. Responsible Trust**

- North
- Belfast
- South East
- South
- West

11. Final Page

Thank you for taking part in this self assessment. We hope you found it a positive experience. We would be grateful for any feedback so that we can improve on future assessments.

21. Feedback

Steering Group Membership

Appendix 4

Donal Diffin	Social Care Commissioning Lead Health and Social Care Board
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