NHS

National End of Life Care Programme

Improving end of life care

Optimising the role and value of the interdisciplinary team: Providing person-centred end of life care

Foreword

"I'm dying, but I'm still living"
(user of a palliative care service)

Preparing to die is hard. The importance of being treated and cared for as a whole person at the end of life, according to one's wishes and with dignity, respect and privacy, cannot be disputed. This level of care is applicable to all people, and to those close to them, regardless of diagnosis and of the place in which they are dying.

Ensuring the person and those close to them has this level of care does not rest with one person or a single professional; rather, it is the responsibility of all those involved in their care, treatment and therapy.

As end of life approaches every individual, whether the dying person or someone close to him or her, is on a different journey. Care provision at this stage is frequently complex, involving a wide range of skills and services from across health and social care. When this care is poorly co-ordinated, it can leave people confused and at times very frustrated, adding to the challenges of preparing for death. As one carer put it, "We didn't realise how much help was available from so many different sources, because nobody pulled it all together and focused it on our needs".

Effective interdisciplinary teamwork, with its emphasis on person-centred communication, is increasingly seen as a way of integrating and co-ordinating care. This guide aims to describe the benefits of this approach and offer practical suggestions for delivering it. At its heart is the principle that both the dying person and their carer(s) are central to the team, not just as recipients of care, but also as participants in it.

To this end, the guide has been developed through workshops, consultation and feedback with people and carers and a range of professionals including allied health professionals, social workers, specialist nurses and doctors. As one carer who attended one of the workshops commented, "the agenda for putting this guide together fulfilled my dream of an integrated approach to end of life care - it was exactly what I, as a carer, was looking for".

This guide describes the kind of high quality care people approaching the end of life and their carers can receive. However, as reported in the first VOICES (Dept. Health, 2012) survey, such high quality care is not necessarily accessible to all people in all care settings. The task of improving care at the end of life will never reach an end point.

As this foreword is being written, the body of knowledge and expertise in how to deliver high quality interdisciplinary care at end of life is rapidly growing. New and revised models of care and policies are being developed to ensure each dying person has a good death, and that those close to them are supported. We hope this guide will make a useful contribution to this vital conversation.

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About this guide

This guide aims to support people working as part of – or alongside – an interdisciplinary team in end of life care. It has been developed with the involvement of a range of individuals and carers with experience of end of life care and of health and social care professionals, via a series of stakeholder events and consultations.

The interdisciplinary team (IDT), sometimes known as inter-professional team or multidisciplinary team, is recognised as a highly effective model of delivering the kind of integrated holistic care that individuals and their carers/families need at the end of life. The teams come in many forms. They may be based within specialist or community settings or may span both. They frequently involve a wide range of professionals, each bringing specialist as well as generalist skills and expertise. Whether the team is formally convened or an ad hoc group supporting an individual, some core principles and systems for effective team working apply.

This guide aims to offer a practical tool for all those involved in providing end of life care through IDTs, in particular professionals who may be part of the team and those managing or co-ordinating IDTs at end of life. The guide:

- Describes what we mean by the interdisciplinary team approach and the benefits of this approach within end of life care
- Discusses what individuals and carers tell us is important about interdisciplinary team working and how this can impact on their experience of care
- Highlights the unique role and contribution of allied health professionals working within IDTs
- Suggests a range of issues that members and managers of IDTs, may wish to consider when planning and delivering care at each step on the end of life care pathway
- Offers practical tips and advice to help improve care provided by IDTs at end of life.

Within the resources section at the back of the guide further information and publications can be found that give health and social care professionals and managers practical advice and tips on how to deliver high quality care to individuals at or nearing the end of their lives and to their carers.

It may also be useful to review guidance produced in the cancer field such as The Characteristics of an Effective Multidisciplinary Team[1].

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[1] Characteristics of an effective multidisciplinary team (MDT), National Cancer Action Team, 2010

Section 1

1.1   Defining the interdisciplinary team

Interdisciplinary team (IDT) working has been defined over the years as the sharing of common goals in relation to the person's care or therapy. This calls for a collaborative approach underpinned by mutual respect, understanding and appreciation of the different roles and contributions that each member makes to the team, including the individual, carers and volunteers. Teams can be actual or virtual and no one size fits all.[2][3]

A range of factors have been identified that contribute to effective interdisciplinary teamwork, from the increasing complexity of skills and knowledge needed to provide comprehensive care, to the increasingly specialisation within health professions, which means **no single professional can meet all the complex needs**[4].

In some services, such as cancer care and specialist palliative care services, the interdisciplinary, or multidisciplinary team as it is often known, is a well-established concept with clear protocols covering both membership and how it should operate[5]. As the new NHS clinical commissioning groups (CCGs) seek to create out-of-hospital care strategies, IDTs are also likely to increase within the community.

In some instances, there will be a well-established IDT group within a locality or setting that comprises a wide range of professionals as in Figure 1. This diagram illustrates person-centred integrated care, underpinned by both organisational and communication processes.

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[4] Barr H, Koppel I, Reeves S, Hammick M, & Freeth (2005) *Effective Interprofessional Education. Argument, Assumption & Evidence*. Blackwell Publishing. Oxford

[5] Reynolds F (2005) *Communication and Clinical Effectiveness in Rehabilitation*. Elsevier. Butterworth Heinmann. Edinburgh London New York.

[4] The impact of enhancing the effectiveness of interdisciplinary working; Nancarrow S et el, National Institute for Health Research Service Delivery and Organisation Programme pp. 58

[5] National Cancer Action Team Manual of Cancer Services, Specialist Palliative Service Measures

Figure 1: Example of a fixed and established core team in a single locality, with the person and their carer at the centre of the team

Person	The person is at the centre and is empowered to communicate their needs and wishes to team members, which are heard and responded to.
Carer	The carer is empowered to communicate their needs and wishes to team members, which are heard and responded to.

Core team

Flow of communication between person, carer and IDT

Elsewhere, not all staff will be part of a formal and established IDT and a smaller core team will be directly involved in ongoing care for an individual, drawing on other health and social care professionals on an ad hoc basis to meet that individual's specific needs, as in Figure 2. This diagram illustrates person-centred integrated care, underpinned by both organisational and in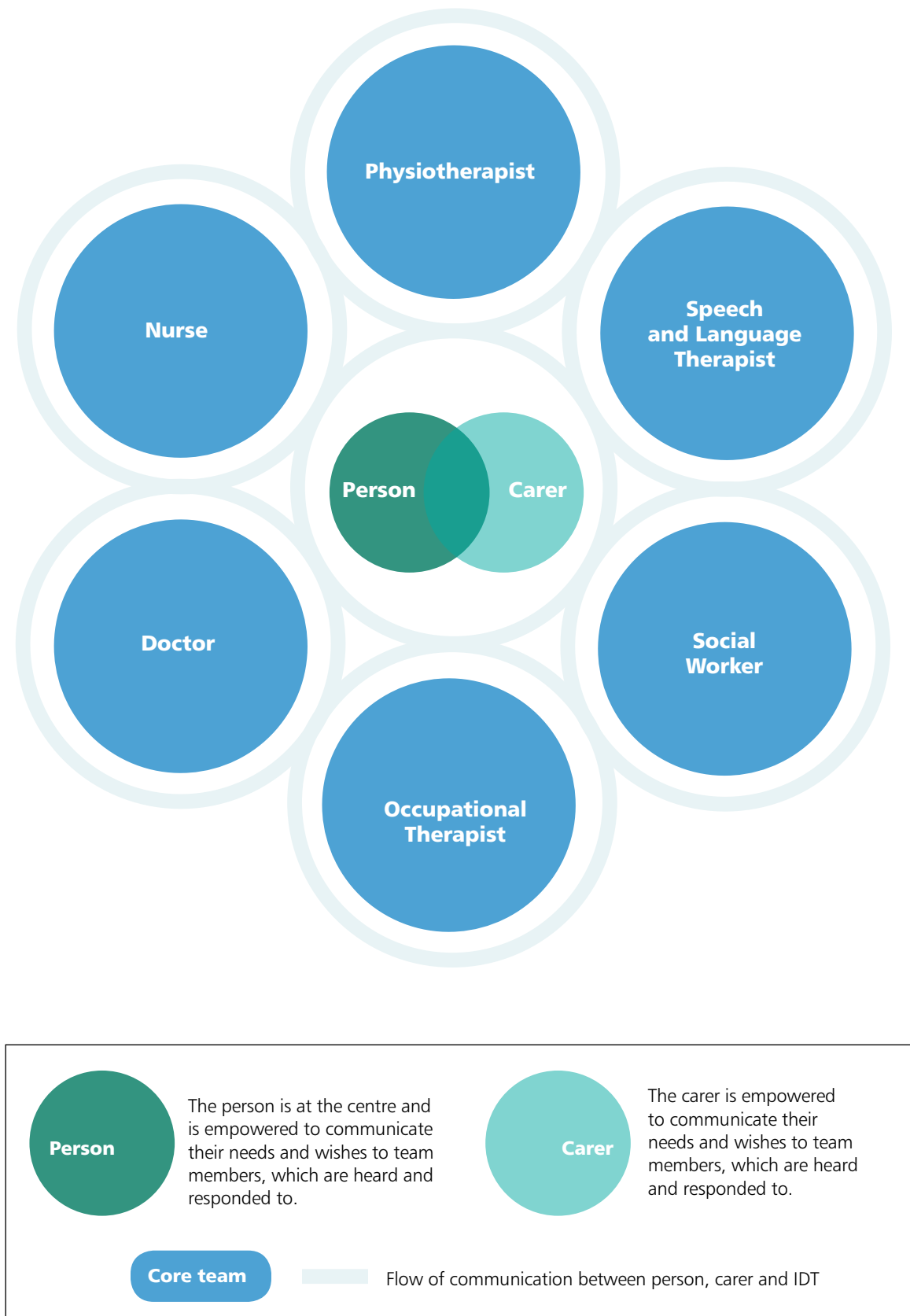ter-agency communication processes. This should happen in whichever setting the person is in, be it hospital or the community.

Figure 2: Example of a flexible extended team, with the person and their carer at the centre of the team
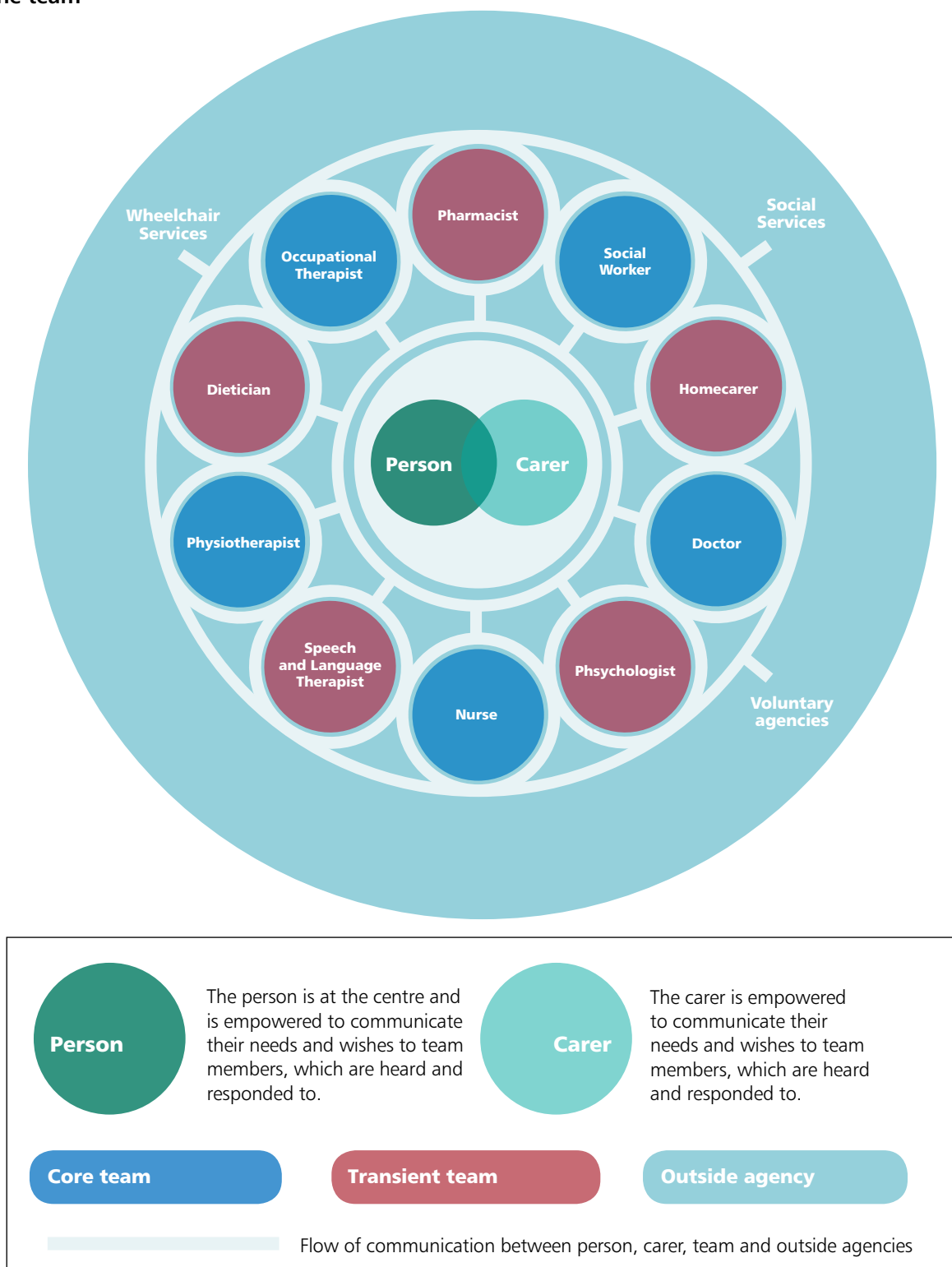
1.2   Defining the interdisciplinary team at end of life

The composition of the IDT in end of life care will vary widely according to local needs and circumstances. The 2008 End of Life Care Strategy describes a range of health and social care staff working in the community, in hospitals, care homes, hospices and other places who have some role in the delivery of care to individuals at the end of their life and their families and carers. It recognised staff will have differing levels of interaction with the end of life pathway, but all at some time will have some form of interaction and therefore need a level of understanding about what good end of life care means.

The IDT in end of life care comes in many forms. There is growing awareness of how effective interdisciplinary teamwork can enhance the care provided to individuals and their carers at end of life[6]. As previously stated no one model fits all but an effective IDT should share some common attributes as shown in Figure 3.

Figure 3: Common attributes of an effective interdisciplinary team

Culture of involvement and coordinated working – all views valued and respected

Use of assessment and care planning tools and frameworks to capture the right information

Strong working partnerships and support mechanisms with clear policies, roles and processes

Effective systems to gather, store and share information – supported by good communication flows in and out

Adaptable, flexible, effective, and responsive IDT working – individuals/carers at the core

Members brought in to meet specific needs – culture of shared, personal and professional responsibility

Commitment to learn from experiences and from user/carer feedback on what works well and what needs improving

Culture of openness and non-hierarchical decision making clearly communicated

Access to specialist expertise including Out of Hours – Specialist Palliative Care accessible in community and other settings

Ensuring the right physical and social environments for care offering dignity and privacy

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[6] Integrated care for frail older people 2012: a clinical overview; Morris J; Journal of Integrated Care, Vol.20 Issue 4 pp257 – 264

1.3   The benefits of the interdisciplinary team approach at end of life

The following two stories demonstrate, on the one hand, the benefits of effective, coordinated interdisciplinary team care and, on the other, the impact that poor or absent interdisciplinary team working can have on the person and their family at this time.

Ian's story

Ian and his wife looked after their daughter Mel when she developed non-Hodgkin's lymphoma. His story shows what a difference it makes when someone receives truly person-centred care from effective IDTs in both acute and community settings.

Although it was very delayed, as soon as cancer was diagnosed a pattern of attentiveness, sensitivity and well-coordinated person-centred care was quickly established. Mel began treatment under a specialist consultant with whom she quickly established a warm rapport. Ian recalls how the consultant got to know Mel personally and used this knowledge of Mel's personal interests and passions – including Liverpool football club – to help build trust.

Although much of the care Mel received continued to be exemplary, there were exceptions. Lack of co-ordination over test results left them anxious and in the dark.

Sadly, it became clear that the cancer could not be cured. Staff were careful to deliver this news with great sensitivity, answering Mel's questions honestly but reassuringly. "No one ever said that they couldn't do anything more." The consultant's personal relationship and knowledge was vital in reassuring Mel and her family at that time.

When Mel was discharged home, the family was very anxious about whether they would continue to receive the high quality care they had had at hospital and felt "as though the safety net was being taken away". However, the communication and co-ordination between the hospital and community services was excellent. The district nurse played a key role in co-ordinating care and supporting the family and ensured essential equipment such as oxygen was available at home, while the lead GP explained the back-up arrangements for care and linked the family to local hospice services. Importantly, the hospital had shared information about Mel – including her passion for Liverpool FC – with the district nurse and local GP, who in turn were able to talk to Mel about it. This attentiveness to little details of Mel's life helped reassure the family that there had been effective communication with the hospital, and that local providers were equally committed to providing person-centred care.

The focus of care now switched to enabling Mel to die at home with her family, and the community nurse and more latterly the hospice nurse helped set up a safe and supportive environment. In the very final stages of her illness, the nurses did what they had to do to make Mel comfortable and then they stepped back to let the family be with Mel. "We didn't know they were there" commented Ian. Mel died peacefully, with her family.

Ian and his family received good care and support after Mel's death, particularly from the district nurse who had become a family friend and continued to keep an eye on the family. It was she who spotted when Ian's grief resurged over a year later, causing him to 'crash' again.

Helen's story

Along with other family members, Helen cared for her father, James, when he developed motor neurone disease. Her story demonstrates how, when the promised IDT care failed to materialise, they were left trying to navigate the highly complex care arrangements and systems alone, with deeply distressing consequences.

When James finally received his much-delayed diagnosis, he and his family were told that an interdisciplinary team would now be 'activated' to co-ordinate and deliver the care James needed. This reassured them that his needs would be met. However, nothing happened. There seemed to be no hurry to put the team in place, and internal communication problems led to further delays. When the team was finally set up, nobody explained to James or the family which health professionals might be involved, and how they could help, for example speech and language therapists helping with swallowing difficulties. In practice there was little continuity of care between the different health professionals involved, such as district nurses.

Little account was taken of the fact that James was himself supporting a wife with dementia. The very different care needs of James and Joan, his wife, were not taken into account by health or social care professionals. It proved almost impossible for the family to organise appropriate care via the professionals to enable them both to remain at home even though all avenues were explored: the professionals and the system did not allow for actions to be taken quickly enough. For someone with motor neurone disease and the very aggressive version that James had, a week can be a lifetime to wait for services to be introduced. It led to James and Joan being separated for a number of weeks as they each received care in different places as the family continued to try and organise care for them both in their own home.

As James' condition deteriorated and he needed episodes of inpatient care, Helen and her family found they needed to 'step in', co-ordinating care and battling for necessary services and carers and trying to locate equipment, resources and information; and all the while having to fight to ensure that their father received the care he needed.

Helen had expected an IDT to help take the strain a bit and then include the family as part of the team with the service user at the centre, but giving the family some space to be with and provide emotional support for their loved one who is dying. "We felt we should have been involved in helping to make decisions about the care but not have been left to managing the whole thing leaving little time for providing emotional support. At one point there were over 40 health and social care professionals involved in her parents' care with only we family members to co-ordinate them all."

As these stories illustrate, individuals nearing the end of life, and those family and friends caring for them, often have complex needs and require a range of treatments, care services and support, and many health and other professionals may be involved. Towards the end of life, when time is precious for the individual and their carer(s), careful co-ordination of the various interventions is particularly important to avoid unnecessary disruptions.

An IDT can be a highly effective vehicle for this, delivering integrated, person-centred end of life care. As well as harnessing a wide range of essential expertise, the IDT is greater than the sum of its parts and it offers its own 'added value' to end of life as seen in Figure 4.

Figure 4: Benefits of interdisciplinary team working in end of life care

Acting as a forum to access, review (including constructively challenge where needed)

It enables teams to effectively target their efforts and resources

Each member of the team will bring a different perspective and understanding of their needs and preferences – all of which are equally relevant and important when planning and delivering care

Being a useful forum for staff to work through the painful emotions that can naturally arise when providing care to people at end of life. These important pastoral support needs are often overlooked

In addition effective IDT working across boundaries and sectors, with its potential to improve early discussion and planning and more efficient co-ordination of care, can also help meet the NHS quality and improvement initiative for end of life care (QIPP) by supporting individuals to die in the setting of their choice and helping avoid unnecessary hospitalisation.

1.4 Simple steps to enhance the benefits of the interdisciplinary approach for individuals and carers

Some of the most effective ways of improving an individual's experience of care are also the simplest. Individuals and carers have the following advice for those planning and delivering services within an IDT:

"Get to know us as people"
It is sometimes all too easy to lose sight of the human being(s) at the heart of the system. Finding out what matters most to them on a personal level and sharing this with other members of the team can make a huge difference to the individual and carer by building confidence that team members are talking to each other as well as demonstrating respect and compassion. The Alzheimer's Society's 'This is Me' leaflet is a good example of how key personal information about the person can be captured and shared.

"Don't make assumptions about us"
Individuals have unique circumstances and needs that may change over time. Those nearing the end of life may have wishes or goals they could achieve with a little creative support; they may be carers themselves with significant responsibility for others. Previously voiced preferences and decisions about care may shift. Individuals and carers may have conflicting views; the primary carer may not be the obvious 'next of kin'. Carers may have feelings of anxiety and distress that they are reluctant to voice. Rather than falling back on assumptions, team members need to ask (and ask again) and then use whatever information sharing systems are in place to pass this information on as appropriate.

"Don't forget about carers"
Many carers will wish to be actively involved in co-ordinating the various elements of care and – provided the dying person is happy with this arrangement – carers can be a tremendous resource to the team. Yet caring for a dying loved one can be extremely painful, and this pain does not end when the person dies. It is vital to assess carers' needs and ensure they can get the support they need to carry out their crucial role within the IDT. This may include practical, emotional and psychological support before the death, at the time of death and for considerable time afterwards.

"Talk to each other!"

When a number of members of a team or teams are involved in assessing or treating a person or carer, it can become frustrating and distressing if this means they have to keep repeating their story and needs to each member in turn. Effective direct communication with the person or carer as well as documenting central discussions via communication systems are key to avoiding this. Every contact with the person or carer is an opportunity to provide high quality care whilst seamlessly transferring and building on the trust established over previous contacts with the team. A simple summary sheet on top of notes, which captures key information – about who is involved, who the person's 'important others' are and personal wishes and preferences – can be very helpful.

"Treat us as part of the team"

Individuals are entitled to be involved in discussions and to take decisions about their care options. Continuous, open, two-way communication between the team and the individual and carer, which respects and promotes autonomy, is essential.

"Be prepared to be flexible"

Arrangements for end of life care can be highly complex. Team members need to keep their focus on the person rather than the system, and to make sure there is scope for plans to be flexible and adaptable. As one carer put it, "the best care often seemed to happen when staff felt able to 'tear up the rule book'"

"Help us stay in control of our care"

Many users and carers welcome the idea of a care co-ordinator or key worker who supports them in co-ordinating the many and varied aspects of care and acts as a primary point of contact. But this does not mean 'taking over' care from the individual and their existing carers, rather it means being sensitive to their wishes and capacity, stepping up and stepping back as required.

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1.5   The contribution of allied health professionals

Most IDTs in end of life care will include a range of Allied Health Professionals (AHPs), including physiotherapists, dieticians, occupational therapists and speech and language therapists, as well as other care professionals such as social workers, and community or hospital pharmacists. AHPs often make a particularly valuable contribution to end of life care delivered through the IDT and with their background they can bring many skills and expertise that add value to the IDT.

The nature of the interventions that AHPs carry out can require them to spend extended periods of time with the person. As a result, they are sometimes able to gain a particularly deep understanding of the individual's needs and preferences, which they can then communicate to other members of the IDT. This enables them to form relationships with families and carers, and they may have an informal role in counselling.

They are also often well placed to take on an informal advocacy role on behalf of the individual/carer, as well as to take on the formal key worker role (though care should be taken to avoid erosion of specialist skills). This can include, with the right training and support, completing Continuing Health Care (CHC) paperwork – a role more commonly assigned to clinical nurse specialists at present.

a) Physiotherapists

The role of the physiotherapist working with a person at the end of their life is very varied. It is generally accepted that patients should have access to an appropriate level of rehabilitation, so that they can function at a minimum level of dependency and optimise their quality of life, regardless of life expectancy. Physiotherapists are well placed, in both the acute and community sector, to assess the persons' physical and functional abilities, including transfers and mobility, and provide appropriate mobility aids and strategies/interventions to maintain the person's safety and reduce their dependency.

Physiotherapists also have a key role in helping patients manage specific disease-related symptoms such as muscle weakness, breathlessness, fatigue and pain, amongst others. Physiotherapists have an important role in helping the person stay comfortable as they near the end of life, through better positioning and by showing them (and their family/carers) how to move themselves around safely.

Because of the nature of the work they carry out with the person, physiotherapists may spend longer with them than other health professionals can. This often enables them to develop a strong relationship and gain a clear understanding of needs and preferences, which they can communicate to others within and beyond the IDT, and may initiate the discussions about when a person would benefit from being supported by the Liverpool Care Pathway.

Role in relation to the IDT	Role in relation to the individual and carer
• Conveying the individual's and the carer's needs and preferences back to the IDT, especially re: new and changing wishes, such as rehabilitation wishes, and/or returning home with care and further support • Feedback re physical status, functional ability and requirements for a safe discharge or to remain at home • Advise IDT re risks and safe moving and handling. Training other IDT members eg in sitting postures • Recognising and acting in a timely manner re falls, new neurology, swallowing difficulties, urgent need for aids/equipment or care review.	• Helping individuals and carers identify goals and wishes and achieve these as far as possible, especially in community settings • Access to appropriate walking aids and equipment • Facilitating the individual's ability to move themselves, and showing family/carers how to do this so that they feel they are able to do something practical to increase the comfort of their loved one • Improved self-management of symptoms such as breathlessness, discomfort and fatigue through education, advice and therapeutic intervention • Positive impact on wellbeing and Quality of Life – living with illness and treatment side-effects.
• May trigger discussions with the IDT about the 'dying phase' (through the LCP).	

b) Speech and Language Therapists

Good communication at end of life is especially important in order for individuals to convey their preferences and choices, their consent and their emotions – as crucial to a 'good death' as the right treatment. Speech and Language Therapists (SLTs) have a key role in facilitating this by enabling those with communication problems to maintain dialogue with care professionals, family members and others.

This includes facilitating the use of communication tools so that other members of the IDT can identify the right intervention. They may also be involved in assessing capacity. SLTs also have specialist skills in assessing and treating swallow function problems and other oral care/saliva management.

Role in relation to the IDT	Role in relation to the individual and carer
• Maximising the contribution of other professionals, by facilitating use of tools and communication aids to identify what intervention is needed.	• Enabling communication between individuals/carers and IDT to support better quality of life • Enabling communication between the individual and significant others.
• Information sharing – SLTs can be key holders of information.	• Early recognition of signs and symptoms through discussion/acknowledgement of change (among both the IDT and individuals/carers).
• Educating professionals to communicate more effectively with each other and with individuals/carers.	• Assessing and deciding whether to treat a swallow function problem.
	• Specialised care such as oral care/saliva management.

c) Dieticians

Nutrition is a key part of care and quality of life as the end of life approaches. Dieticians may operate in a range of settings and offer guidance to other professionals on oral and non-oral feeding.

Role in relation to the IDT	Role in relation to the individual and carer
• Primary role in education of other health care professionals.	• Improving individual's quality of life through provision of practical advice (for example food fortification), assessment and management of symptoms affecting nutritional intake.
• Development of relevant written information for individuals and carers.	• Addressing concerns of family, carers and other health care professionals with the aim of setting realistic goals e.g. a shift of focus from body weight to maximum enjoyment of food and reduced anxiety.
• Interface between acute and community dietician.	• Prescription, monitoring and management of artificial feeding if appropriate.
• In complex cases, assisting in judging whether artificial feeding may not be appropriate.	

d) Occupational Therapists

Occupational therapists (OTs) have a key role in enabling a person to participate in (occupations) activities which are important and meaningful to them (personal, domestic, vocational and psychosocial activities) including any new activity. This role is as key at the end of life as at any other period in the person's life.

OTs also have a key role in facilitating the person's environment to enable the person to achieve this participation. Enabling a person to return to or stay within their home or their place of preferred care will be key occupational therapy practice within the end of life care pathway.

Role in relation to the IDT	Role in relation to the individual and carer
• Feedback to team: the individual's choice of activities, their ability to complete the activities, advise on what, if any assistance the individual needs to do the activities, carers needs • Discharge planning: liaising with immediate care team, sharing assessment results including home visit outcomes. Advocating for the individual in relation to their desired place of care • Joint working with physiotherapist and speech and language therapist • Liaising with community agencies social services, specialist palliative care services (dependent on the setting in which the individual or carer is being seen in).	• Enabling the person to set realistic goals through functional assessment and /or home assessment • Assessment and recommendation for home adaptations, equipment including assistive technology, environmental controls, telecare and/or practical support. Possible advocacy for the above. Includes assessment of needs and abilities of carer* • Referral to carer support services before or post bereavement • Seating and posture management • Asses the activity needs and abilities of the carer • Referral to community agencies social services, specialist palliative services (dependent on the setting in which the individual or carer is being seen) • Provision of anxiety management.

dependent on carer wishing to carry on caring and the individual wishing carer to continue caring.

1.6   The contribution of social workers

Social workers and the wider social care sector have an important role in supporting individuals with end of life care needs as approximately 30% of people use some form of local authority funded support in the last year of life.

As part of their statutory duties, social workers undertake holistic assessments of need for service users and carers. They commission a full range of care and support services such as personal care, long term support, personal budgets, practical support, respite care, access to community services. They also respond to safeguarding, concerns, complete capacity assessments for individuals with mental health needs and undertake case work with families. They are deployed in a range of settings (community, hospital, specialist teams) and different service areas such as older people or adults with learning disabilities.

Social workers can be at their most effective when working closely with other professionals as part of interdisciplinary teams. Where co-location of health and social care staff takes place this can transform the way person-centred care and support is arranged and provided. The following table sets out more clearly the valuable role social workers have.

Role in relation to the IDT	Role in relation to the individual and carer
• Undertaking statutory assessments of need in relation to community care services, mental health assessments, carers assessments and safeguarding adults • Working with individuals and carers to plan and arrange services • Promoting health and wellbeing, recovery, living well dying well and positive outcomes • Supporting informed decision making in relation to end of life care and support • Oversight and lead professional responsibilities in co-ordination of complex packages of care and support in interdisciplinary teams in a range of settings (hospital, community) • Casework with individuals and carers, including counselling • Monitoring and review of social care services • Commissioning, development and liaison work with partner agencies such as primary care, hospices, the voluntary community and faith sector.	• Working with individuals to identify their care and support needs and making vulnerable adults safe • Ensuring services are tailored to meet individual needs • Enabling and supporting individuals to make informed choices and live well • Ensuring advance care plans are in place and end of life care is well planned • Ensuring well co-ordinated delivery of care and support • Therapeutic support • Ensuring services adapt to changing needs • Service improvement and innovation.
• Advice, information and signposting to wider networks of support.	• Rights and entitlements (financial, income, benefits).
• Quality assurance to ensure outcomes for individuals are being met.	• Ensuring consistent and high standards of service quality through different stages of end of life care and support.

Section 2

Promoting effective interdisciplinary team working across the end of life care pathway

While there is widespread recognition of the benefits of the IDT approach, a range of barriers to effective interdisciplinary team working in end of life care create challenges, and creative solutions to meet these challenges are highlighted throughout this guide within the case studies. Figure 3 showed the attributes that help to promote effective interdisciplinary team working with the individual, their carers and families at the core.

To help keep these core attributes to the forefront of day to day working the following issues are highlighted and should be considered by members of the IDT. This will enable them to be better prepared to address the issues as they arise by ensuring that the information is available, communication has supported a plan for coordinated action, and that someone within the team is responsible and ready to respond or take further action.

a) Issues that concern the individual and the carers

- Who am I seeing today and what is their role in my care? How will they help me and will I be able to trust them?
- Is everyone in my team aware of my wishes/preferences and care plan and of their role in my care?
- How will information about me be shared, and with whom? How can I see what information is being held about me? Who is co-ordinating my care? Has this changed – has there been a handover?
- What happens to my team if I have to move to another setting (back home, another ward or treatment centre)?
- Who do I talk to about other health problems such as long term conditions?
- What are my options for care and who can help me decide?
- Who will tell me about non-health related aspects, such as benefits?
- Who do I talk to if something changes?
- Who can support my carers?
- Where can I get written information about my condition/end of life care?
- Who is my key worker and how can I contact them?

b) Issues that an IDT member should consider

When coming into contact with an individual/carer at any point along the end of life care pathway, members of the IDT should consider:

- Does this person know who I am and what is my role in their care?
- What does this individual (and carer) know about their diagnosis and prognosis?
- What is this person's situation (including wishes/preferences, and relevant relationship dimensions as well as their health status)?
- What really matters to this individual? How can I ensure this is communicated to others involved in their care?
- Who is the care co-ordinator/key worker, and who holds the information/documentation on this person?
- Who else is involved in caring for this individual? What other conversations have been had within the IDT? With the individual or carer? Might their needs or preferences have changed recently?
- Have my recommendations been followed through? Can I check?
- What other services are available within and outside my team, which this person could benefit from?

■ Are my competences[7] in this area up to date and at the correct level and which referral protocols and policies apply in this situation?

■ Who will I be handing over care to, and what information does that member of staff need to see in order to be able to provide the right care? Have I obtained informed consent to share this?

c) Issues that IDT managers should consider:

■ How can we develop a culture of openness and shared personal and professional responsibility among all staff coming into contact with individuals nearing end of life?

■ How can a culture of team decision-making be developed, avoiding a hierarchical approach where the expertise and insights of AHPs or other non-'core' members of the team may not be fully utilised?

■ Do our information sharing systems meet the needs of the individual, carer and IDT, balancing convenience and the need for shared access against security and confidentiality requirements?

■ Are adequate protocols in place for obtaining consent for sharing information, including between health and social care?

The following two case studies demonstrate work undertaken in two areas to improve effectiveness of working within IDTs in their areas.

Case study 1

A toolkit to evaluate and develop the effectiveness of the IDT

Merseyside and Cheshire Palliative and End of Life Care Network have commissioned a pilot programme designed to support integrated multidisciplinary teams (MDT) in evaluating and developing the effectiveness of their team. The programme was developed by a group of local palliative care professionals via an action learning set and draws on National Cancer Action Team guidance and the Peer Review measures.

The programme includes a tool kit consisting of:

■ A questionnaire for the MDT lead clinician

■ A questionnaire for members of the integrated MDT

■ Evaluation of results for each integrated MDT

■ Bench marking of MDT results against other teams in the Network and linking of MDT Lead responses to individual MDTs

■ Access to dedicated resources through the MCCN website including examples of best practice and useful documentation e.g. policies, significant event analysis tool

■ Easy access/regular updates on current literature/references relating to MDT working

■ Suggestions for training and development opportunities for MDT members

■ Option for local peer review of the MDT (future development).

The first step is for individual members of Integrated MDTs to participate in the questionnaire survey that is done electronically. The questionnaires have been developed to help teams reflect on how their MDT functions and allow integrated teams to self-assess themselves against both the current national measures of best practice and other integrated MDTs within the Network. Results are analysed and will provide individual MDT feedback and benchmark against others in the Network. MDT Leads will fill in an identical questionnaire but and their feedback linked to their own MDT.

MDTs will then be able to use the results to help focus on areas which may be helped by increased training and development. The questionnaire may also be of use to clinical meetings/groups who are not part of the Peer review process.

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[7] Developing end of life care practice - A guide to workforce development to support social care and health workers to apply the common core principles and competences for end of life care (2012)

Case study 2

Implementing an end of life care pathway and electronic palliative care co-ordination system (EPaCCS) through a CCG

North Hampshire Clinical Commissioning Group covers a population of 216,000 and 22 GP practices. End of life care (EoLC) has been a strategic priority since the creation of the Clinical Commissioning Group (CCG) and an EoLC group has been in place. All key stakeholders are involved including Hampshire Hospitals Foundation Trust, Southern Health Community Trust, Hampshire County Council Adult Services and St Michael's hospice in the EoLC group that meets quarterly. The first job was to review the current patient pathway and the ideal one to ascertain any gaps and the services that were required. This led to the launch of the EoLC pathway in May 2012 that has been shared with all local GP's, community nurses, the local Health and Wellbeing Board and the ambulance service.

The first step of the pathway is identification of individuals in the last year or so of life this is closely linked to the national Find the 1% Campaign and the region forms one of the local area action zones for this. In November 2011 Integrated Care Teams were established and an important part of their role and the identification of their caseload was the 1%. Identification is achieved by using the surprise question. The CCG has also been using Aggregated Combined Group (ACG) predictive modelling for long term conditions and this has also been used to identify the 1%. 1% of patients are also included from current supportive care registers, virtual ward, patients with two or more admissions in the last six months, patients in care homes and patients with severe long term conditions.

The next step on the pathway is obtaining consent and entering the 1% onto the EPaCCS. The register was launched in August 2012 and training and patient entry is ongoing. This training forms part of the overall EoLC education of the workforce and ways of achieving this within integrated care teams particularly around facilitated advance care planning and communication training are being identified. Each GP practice has a nominated EoLC lead and EoLC meetings are held at least monthly to discuss all of those on the register particularly 'red rated' individuals who are rated by complexity as well as prognosis as opposed to prognosis alone. The keyworker model is being considered and identification/registration leads to the opportunity for advance care planning being offered to patients and their carers.

To ensure all of this work is maintained these areas, which form the key QIPP areas, are represented in the CCG Operating Plan and Commissioning Intentions. In March 2012 a CCG LES was also developed to support the pathway. The LES covers:

i)   identify practice 1%,

ii) draw up palliative care strategy plan i.e How to manage this 1% list,

iii) monthly review of list-READ codes and care planning,

iv) After death audit July 2012 – Jan 2013.

Importantly for patients, identification and registration on the 'gold register', entitles patients to receive a 'gold care' card which includes key contact details. This scheme launched in May has been welcomed by patients: "If I am taken ill or whatever, doctors will know exactly what I need without me or my wife having to explain what's the matter with me. It just makes it that bit easier to get the right help for me."

Contact:

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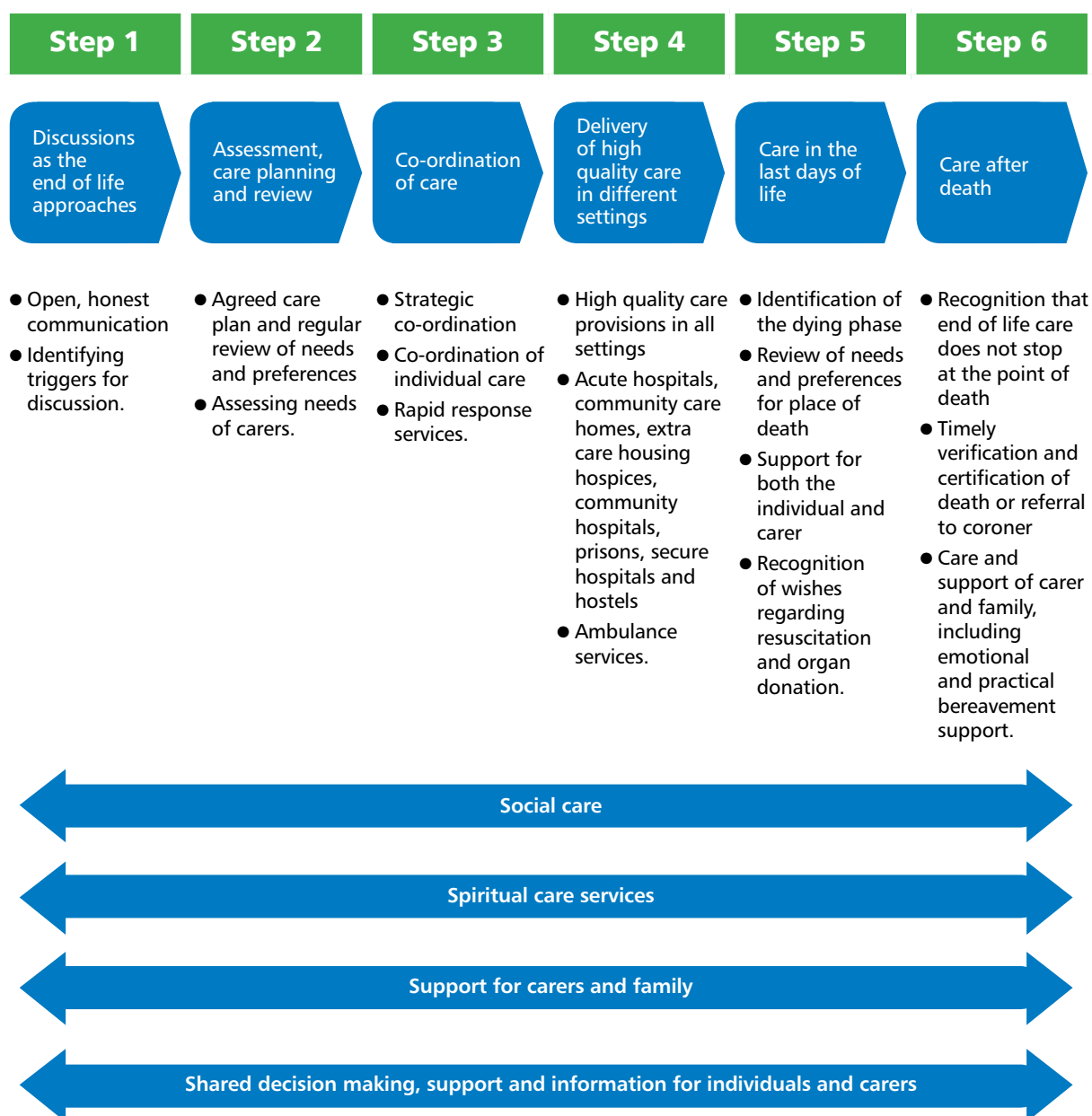**charlottehutchings@nhs.net**

Resources and further information

- **End of Life Care Quality Assessment tool (ELCQuA)**
- **EPaCCS implementation network**
- **15 Steps Challenge – Quality from a patient's perspective**
- **Find your 1% campaign**
- **NICE Quality Standard for end of life care**
- **NICE Quality Standard for patient experience**
- **National Cancer Action Team Manual for Cancer Services, Specialist Palliative Service Measures**
- **National Cancer Action Team Characteristics of an effective multidisciplinary team**
- **National Council for Palliative Care What about end of life care toolkit**
- **National survey of bereaved people (VOICES), ONS/Department of Health**
- **Carer Watch's Blog**

Section 3

Effective interdisciplinary team working at each step on the end of life care pathway

Figure 5: The end of life care pathway

Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
Discussions as the end of life approaches	Assessment, care planning and review	Co-ordination of care	Delivery of high quality care in different settings	Care in the last days of life	Care after death
• Open, honest communication • Identifying triggers for discussion.	• Agreed care plan and regular review of needs and preferences • Assessing needs of carers.	• Strategic co-ordination • Co-ordination of individual care • Rapid response services.	• High quality care provisions in all settings • Acute hospitals, community care homes, extra care housing hospices, community hospitals, prisons, secure hospitals and hostels • Ambulance services.	• Identification of the dying phase • Review of needs and preferences for place of death • Support for both the individual and carer • Recognition of wishes regarding resuscitation and organ donation.	• Recognition that end of life care does not stop at the point of death • Timely verification and certification of death or referral to coroner • Care and support of carer and family, including emotional and practical bereavement support.

Social care

Spiritual care services

Support for carers and family

Shared decision making, support and information for individuals and carers

The end of life care pathway (Figure 5) offers a framework for considering how to deliver care at each stage or 'step' on the person's journey through end of life care. While there are many common features, challenges and enablers to effective IDT working across the pathway, there are also some specific issues which arise at each of the six steps.

Each of the following sections describes the relevant issues applying at that step on the pathway and sets out issues and questions for members of the IDT and service delivery managers (or their equivalents) to consider. It also offers some practical advice in the form of 'top tips'.

3.1   Step 1 – Discussions as end of life approaches

Open and informed discussion with the individual and their carers about their wishes and preferences for end of life care, preferably while the individual still has capacity to make informed decisions, is vital to anticipating and planning future care. However, identifying when individuals are approaching the end of their life can be complex; the stages of deterioration can themselves be unpredictable.

Discussions about prognosis and disease management will usually be conducted by clinicians, but anyone in the wider team working with the person, including social care workers, may pick up cues and clues that the individual is moving towards end of life; all staff therefore need the skills and confidence to recognise signals and initiate appropriate action. This necessitates a culture of openness among staff, which acknowledges when a person is reaching end of life, and promotes discussion and planning with the individual/carer and within the IDT; and for provision of suitable training.

These discussions, although vital to enable ongoing co-ordination of care, can be unsettling and distressing for both individuals and carers, especially if this is the first time that a diagnosis or prognosis has been openly discussed. There may be an initial shock reaction and individuals may need more time to absorb information before taking further steps. The knowledge that an IDT will be involved in providing care can be highly reassuring, as long as the various roles of IDT members are made clear.

Users and carers can have differing needs and concerns at this stage. Staff will need to be sensitive to the impact of cultural beliefs and values and family dynamics on the situation. Maintaining dignity is crucial; several actions have been identified for dignity-controlling symptoms including:

- listening to the person and taking them seriously
- providing advice concerning how to cope on a daily basis
- treating individuals as equals and with respect
- encouraging the family members' presence[8].

While active involvement of carers can be very beneficial, some individuals may not want to involve their carers. This can cause tensions and professionals may need to encourage more open dialogue, while ensuring that the person's wishes are respected. Sometimes it may be helpful to hold separate discussions, where all parties have agreed.

Crucially, each member of the IDT needs to know what information has been gathered and where it is stored; and what conversations have taken place, particularly about prognosis. It is also important to consider how information gathered by members of the IDT will be shared within the team, and to ensure informed consent has been obtained for this.

> **"As our son began his journey though treatment, no-one seemed to be thinking about the impact it was having on us as a family, or how to involve us in care. Frequently, the consultations were with our son on his own and it was never clear "who knew what" about his condition or his prognosis."**
>
> Tony, father and carer of Neil

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[8] http://www.ejoncologynursing.com/article/S1462-3889(11)00126-8/abstract

a) Issues for IDT members to consider:

- What are the cues and clues that may indicate someone is ready to talk about death and dying and what skills and knowledge do I need in order to feel comfortable with these discussions?

- If someone indicates they are ready to discuss this, am I the best person to hold discussions about preferences at end of life? If not, how will I ensure that this is followed up by the right person? Who else do I need to tell?

- Have I checked what the individual or carer know about the prognosis, and what information colleagues have already gathered?

- How much involvement does the individual wish their carer to have? How much involvement does the carer wish to have? Would a separate discussion with carer(s) be helpful?

- What are the limits of my professional competence and what referral protocols are in place?

b) Issues for IDT managers to consider:

- Who within the IDT is able to conduct initial conversations about end of life and do they have the necessary communication skills for this?

- What communication skills and training do other members of the team need in order to recognise cues and clues that end of life may be approaching and take appropriate action?

- Are staff aware of their obligations in relation to safeguarding?

- Is there adequate time and the right environment – ideally private – to enable sensitive handling of initial discussions with the person/carer? How can this be achieved?

- Do IDT members understand each other's roles and contributions? If not, how could education, training and team meetings be used to develop this?

- Who within the team (or outside it) can provide information on non-health matters such as benefits?

Top tips

- Find out what the individual and carer(s) know about their prognosis before initiating discussions, but avoid 'shielding' them: balance the need to give some hope against providing a realistic picture of what to expect

- Don't assume the individual or carer fully understands their situation - allow time to check this; ideally, try to obtain an 'I understand the situation to be...' type statement

- Ensure there is access to psychological or bereavement support through the IDT at the time of diagnosis/prognosis

- Provide written and verbal information on care, including on available options, but be aware that individuals may need time to absorb news first

Top tips

- Minimise the number of discussions with different members of the IDT at this stage, when individuals may still be taking in the news of their diagnosis or prognosis

- Encourage the individual (or carer) to record personal information about themselves that they would like others to know (e.g. using 'This is Me' type leaflets)

- Keep a separate record of discussions with carers

- Ask 'who else do I need to pass this information to, and how?'

- Be proactive and timely when making onward referrals to other health and social care professionals

Case study 3

Carers Directory to help individuals find the right support

Staff at Clatterbridge Cancer Centre and the Merseyside and Cheshire Cancer Network have developed a Carers Directory which gives up to date information on support groups, services (including from local authorities in the area) and useful contacts. This complements a guide to services available from local support groups.

The team involved in developing the resource, including an Occupational Therapist, Macmillan Welfare Rights officer, Macmillan information officer, older person lead in the hospital and social worker, recognised that while carers play a central role in providing support to individuals, they often do not experience a cohesive integrated system of social support. So, after researching what was available in the area, the directory was developed. The directory has recently been introduced and will be evaluated. Staff anticipate that providing carers with adequate information and additional support will hopefully help both the person and the carer, and prevent hospital admissions and further stress on both carer and the person.

The guide can be found at **www.mccn.nhs.uk/index.php/patients_cancer_help_and_support**

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Case study 4

The AMBER care bundle

The AMBER care bundle was developed at Guy's and St Thomas' Hospital to support teams in identifying and responding to a person's end of life care needs when their recovery is uncertain. It is designed to enable treatment to occur alongside palliative care.

The tool incorporates and is supported by a package of interventions which includes staff training and development required to embed the tool in daily ward and operational practice.

The simplicity of the tool belies the complexity of problems it addresses. These include issues around recognition of end of life care needs in an acute hospital setting, managing uncertainty, communication and engagement.

More information on the AMBER Care Bundle can be found at: **www.ambercarebundle.org**

Case study 5

Find your 1% campaign

Around 1% of the population will die within a 12 month period. Many will have unplanned and sometimes lengthy admissions to hospital during this last year of life and too often their needs and preferences, including preferred place of death, will not have been assessed or recorded.

Under-identification of individuals nearing the end of life is a widespread problem: a recent snapshot survey found that only 27% of people who were in their last year of life were identified by GPs and included on a palliative care register. Yet statistics show that just 8% of deaths in any given year are entirely unpredictable.

The Find your 1% campaign, developed by the National End of Life Care Programme in partnership with the Dying Matters Coalition, aims to address this through a call to action for GPs to proactively identify the 1% of their local population who are likely to need end of life care over the following year. GPs are asked to sign up to the campaign, signifying their commitment to find their 1%, in order to talk about, plan and make possible individuals' wishes at the end of life.

Once the person has been identified, and the necessary conversations held, their wishes can be entered onto the local end of life care register, which will enable better co-ordination of their care and allow GPs and others to track improvement in identification.

This campaign is one strand of work to support the QIPP end of life care workstream and more information can be found at: **www.dyingmatters.org/gp**

Resources and further information

- ■ **National End of Life Care Programme resources on discussions as the end of life approaches**
- ■ **Alzheimer's Society 'This is me' leaflet**
- ■ **The AMBER care bundle**
- ■ **Carers Direct**
- ■ **Dying Matters resources**
- ■ **e-ELCA communications skills modules**
- ■ **'Finding the words' workbook and DVD**
- ■ **ISB information standard core dataset for care co-ordination**
- ■ **NHS Choices**
- ■ **RADPAC – RADboud indicators for Palliative Care Needs** [9]

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[9] Early identification of and proactive palliative care for patients in general practice, incentive and methods of a randomized controlled trial, Bregje Thoonsen, *BMC Family Practice* 2011, 12:123

3.2   Step 2 – Assessment, care planning and review

Sound assessment and care planning is at the heart of providing high quality end of life care. Holistic assessment offers an opportunity to gain a full understanding of the hopes, needs and preferences of the individual and, equally importantly, any carers involved – to build a picture of the individual and their situation in the fullest sense, in order to provide genuinely personalised care.

Assessment itself is only a starting point: needs change, often quickly and unpredictably, and ongoing review, re-assessment and adjustment of the care plan will be necessary. The IDT can be a valuable vehicle for this, as other members of the team – for example AHPs – can offer a 'fresh pair of eyes', alert to triggers, cues and clues that suggest a further review may be necessary.

Several members of the IDT may need to carry out an assessment but it is important to avoid overwhelming individuals with different assessments. Each IDT member needs to be clear on their own role within the pathway. They should also be able to access and update information and plans in order to minimise unnecessary intrusion and repetition for individuals and carers. Effective information and communication mechanisms are key to achieving this.

Electronic palliative care co-ordination systems (EPaCCS) – and 'patient-held' records can be very effective, although they can take time to put in place. In the meantime, it can be very helpful to capture and share key information about who is involved (including personal wishes and preferences) and who the person's 'important others' are. Regular updating of the care record is important, in particular when there is a change in the person's condition.

Systems for recording and sharing information are changing rapidly, but whatever the system in place, the same principles of good practice will apply.

> **"I see multiple clinicians for my various conditions, and each time I have to 'start again' explaining my condition and needs. You have to hold your own information – be your own expert."**
>
> Mandy, individual with end-stage COPD and carer for members of her family

a) Issues for IDT members to consider:

■ Does the individual need support to communicate, for example from a Speech and Language Therapist?

■ Is the person nearing end life also caring for someone else?

■ Have the needs of carers been assessed?

■ How will I share information with other members of the IDT, including social care? Do I have informed consent for this from the individual and/or carer?

■ Who else, beyond the IDT, do I need to share this information with (e.g. ambulance services)?

■ Have the outcomes of the assessment – including care plans – been shared with the individual and carer in an accessible format as well as with other members of the IDT?

■ What are the triggers, cues and clues that may suggest that a person or carer's needs should be reviewed?

b) Issues for IDT managers to consider:

■ Are effective mechanisms in place for sharing and updating plans and information, including with key personnel and services 'outside' the IDT (including the GP and ambulance service)?

■ Is there training in place for all staff involved – including formal carers such as agency home care providers – in the processes, documentation and status of the various planning tools and mechanisms?

■ What opportunities can be created for AHPs and others to offer a 'fresh pair of eyes' on the person/carer's needs?

■ How can we keep the number of 'interventions' for assessment reasonable and manageable for the person/carer, avoiding repeated lengthy formal processes?

Top tips

- Find out who are the significant others in the person's life – and think 'wide' when considering their needs. Pets, for example, can be very important to individuals
- Be aware of family dynamics and the tensions that may arise between the needs and preferences of individuals and their carers
- When talking to carers, do not just ask "Are you ok?" – ask follow up questions (e.g. "Are you sure?") to give them a chance to share their true feelings
- Help the individual and carers to anticipate and plan for future needs as far as possible
- Build questions such as "have you informed ambulance services of an individual's end of life status?" into documentation and guidance for staff carrying out assessments

Top tips

- Capture key information using a simple summary sheet which can be kept at the front of the individual's notes
- Don't reinvent the wheel – take into account any assessments that have previously been carried out
- Consider arranging extended specialist palliative care IDT meetings, so that community based professionals can present complex cases and situations to the specialist palliative care team. These could be held in specialist or community settings to improve communication and mutual understanding of roles.
- Ensure consent has been given to share information with other professionals and settings

Case study 6

Long term condition review clinic to improve care and management in the community and prevent crisis

A community rehabilitation team in London has established a long-term neurological condition conditions review clinic to monitor and address individual's changing needs and act as a preventative measure for 'crisis' interventions.

Staff had found that individuals with these conditions frequently had involvement from several agencies and were often referred to services at times of crises; they also sometimes had difficulty accessing services when they needed them.

The new review system addresses this through regular review, via a team panel discussion or a direct review with the person, either face to face or by telephone. Reviews take place at 3, 6 or 12 monthly intervals dependant on level of need. A summary of every review is sent to the person, GP and consultant if relevant after the review. The reviews are then discussed at the panel meetings and a summary of discussions including actions and plans is circulated to panel members. This is all done via confidential fax or secure email etc. Panel members also receive a summary prior to the panel so that they can gather information prior to panel meetings on the person's status within their service to inform planning reviews.

The review clinic was set up with input from the community neurorehabilitation service, district nurses, social services, social services OT, palliative care nurses, voluntary agencies (e.g. MNDA) and others. Individuals consent to involvement from the review clinic and to share their information between agencies.

Reported outcomes for the person and carer include improved coordination of care, fewer referrals with conditions in crisis, and reduced duplication of intervention. Staff report it has also improved joint working within the multidisciplinary team and between agencies working with these clients.

This service is currently undergoing an evaluation as a learning process for improving running of the review clinic.

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Resources and further information

- **National End of Life Care Programme resources on assessment, care planning and review**
- **Carers Direct carers assessment**
- **Carers UK**
- **It all ADSE up – Advance care planning toolkit**
- **Holistic common assessment**
- **Preferred priorities for care**

3.3   Step 3 – Co-ordination of care

Individuals nearing the end of life frequently receive care from many different professionals and services, whether in a hospital or community setting. The varying elements need to be carefully co-ordinated to minimise disruption and delay for the person/carer. An IDT can be an effective vehicle for co-ordinating care, but there can be practical challenges, particularly if it operates across boundaries and settings. Effective communication and information-sharing systems are therefore paramount.

Given the complexity of end of life care, the concept of a key worker or care co-ordinator has great appeal, including to individuals and carers. The GP is often considered the default care co-ordinator and while s/he may not be in routine contact with other members of the IDT, s/he remains an integral part of the team and needs to be involved in decisions and kept up to date with developments. Increasingly, EPaCCS registers are in place making it easier to identify and hold information on both individuals with cancer and those with other conditions. On a practical level, other members of the IDT, including AHPs, are also often well-placed to take on the care coordinator role.

At the same time, the extent to which the individual or carer wishes to be directly involved in co-ordinating the care will vary from case to case. Some may wish to proactively co-ordinate the different services and individuals, for at least some of the time; here, IDT members, including any named care co-ordinator(s), will need to be prepared to step up – or step back – in accordance with their preferences and capacity. Others may not feel able to be actively involved and here the IDT members will need to take on a greater role in co-ordination.

> **"It felt like we needed someone to co-ordinate the care my dad needed – similar to conducting an orchestra. Just like the conductor has an overview of the music score, a co-ordinator would have an overview of a person's whole situation and care plan. They could then bring in the different instruments (services) to play when they are needed according to the music (care plan) so they are all playing in harmony (co-ordinated). This would have been sweet music for us."**
>
> Helen, carer for her father

It remains vital to keep the focus on the individual and carer and to ensure that they are kept up to date on arrangements. This includes advising them who is co-ordinating their care, and informing them in the event of a handover to another professional/team; and informing them who to contact for more help should circumstances change.

a) Issues for IDT members to consider:

- Is there a named care co-ordinator and has the individual/carer been advised who this is, and how to contact them?
- Has the individual/carer been kept informed of any changes to these arrangements?
- Has the individual given their consent for their information to be shared with other services?
- What really matters to this individual and their carers? How can I share this information with others working with them?

b) Issues for IDT managers to consider:

■ Is there a forum for engaging all agencies involved in providing care to the individual/carer, i.e. not just the immediate multidisciplinary team?

■ Is there a mechanism for appointing a key worker/care-coordinator/point of contact? If the key worker or co-ordinator of care does not have routine contact with the team, if they are a GP for example, how are they kept informed of developments?

■ Are the right tools, policies and protocols[10] well understood and in regular and consistent use across all organisations involved in delivering end of life care? These should be holistic, and cover wider spiritual and practical issues as well as clinical needs.

■ How is information gathered, stored and shared within and beyond the team and across sectors and what are the legal issues around this?

■ If the IDT is hospital-based, how will a rapid response be provided, co-ordinated and communicated when the preferred place of care is elsewhere (e.g. the person's home or care home).

Top tips

• Ensure that what is important to the individual, in addition to their preferences for care, is known and communicated within the team and across agencies

• Capture key information about the person – who is involved in care, preferences, significant others etc. – on a single sheet of paper that can be easily accessed and updated in their records

• When in key worker role, be prepared to pass the baton on to others

• Where a face to face IDT meeting has been held without medical input, ensure the person's lead doctor/GP is kept up to date with outcomes

• Share information and records with the person and carer and encourage them to ask their GPs to make use of information sharing systems

Top tips

• Give the person or carer a simple card explaining who to call in different scenarios, e.g. difficulties in swallowing or moving around

• Look for ways of increasing understanding of the different roles within the IDT and ensuring cross communication about individuals' care, e.g. by attending GSF meetings or equivalent

• Aim to introduce registers such as EPACCs, but look for interim arrangements which help bridge the gap

• Look for ways of bringing acute and community based IDTs together to improve communication and mutual understanding

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[10]Such as Preferred Priorities for Care, Do Not Attempt Cardiopulmonary Resuscitation, Advance Decisions to Refuse Treatment, the Liverpool Care Pathway and Rapid Discharge Home to Die Pathways

Case study 7

Co-ordinating care through Integrated Specialist Palliative Care MDT meetings

The outreach team at Willowbrook Hospice have been proactively involved in producing a formalised policy and supporting procedures for integrated specialist palliative care MDT meetings. The initiative aimed to improve communication between the various disciplines and cross-site boundaries involved in caring for individuals and their families.

All staff with a key role and expertise in end of life care were involved in the initiative, including the hospice's allied health professionals (occupational therapist, physiotherapist) and psychosocial team (social worker, chaplain and family support co-ordinator). This reflected the need to respect all disciplines input when discussing clinical management plans rather than solely focusing on medical and nursing input.

A new pro-forma for weekly use was devised, piloted and then fully implemented across the integrated services for greater efficiency. As a result there is more opportunity for relevant discussion that is inclusive of all disciplines. Complex discussions can be held that result in better support for staff and improved care management outcomes. An expert group then puts in place realistic plans and recommendations that have a direct positive impact on the person and/or family.

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Case study 8

Greater integration of services through a partnership of local providers

Bedfordshire's Partnership for Excellence in Palliative Support (PEPS) pilot was the result of a shared frustration among patients, carers and staff that individuals were not always able to find the right service when they needed it at the end of life. NHS Bedfordshire was also facing a national target to increase home deaths. Greater integration between the services involved in end of life care would not only benefit patients, their families and carers but also produce savings from cutting unnecessary hospital admissions.

Having gained approval from NHS Bedfordshire, the team set up an operational group of all the partners to consider what these new services should look like. It reviewed the current service provision, identifying what would need to be extended and what new services introduced. It also worked out how the services would dovetail with each other.

A central electronic register was established containing relevant information on those in the last year of life to which all services would have access. The incentive for patients was that once on the register they would have a single point of contact, available 24/7, for all their future needs.

The one-year pilot is based on a 'hub and spoke' model with the hub being a 24/7 palliative care co-ordinating centre provided by Sue Ryder at St John's Hospice. This links to all the services provided by the partnership organisations. Health and social care professionals will identify individuals eligible for PEPS and will then offer them the opportunity to register with the service.

The partnership is underpinned by a 'memorandum of understanding' between the 15 different local organisations involved, including the hospices, the ambulance service, acute hospitals, local authorities, voluntary and community organisations.

The service went 'live' as a pilot on 29 December 2011. By the end of May a total of 470 patients were registered with PEPS, of whom 266 had died. Just over two thirds (68%) of these deaths were in individual's usual homes – including care homes – with 22% dying in a hospice and only 10% in hospital. Of the 100 who had indicated where they wished to die, 87% opted for their usual home and only 1% for hospital.

Meanwhile the proportion of deaths in hospital in the area dropped from 57% to 48% by March 2012 while home deaths rose from 34% to 43%. PEPS has already exceeded its own target of having 200 people on the central register by the end of March.

The service has also proved popular with patients and their families. District nurses have also been reassured. They know now that if they need more support they can refer a person to the palliative support worker who can sit with them through the dying phase if needed.

A top priority is getting as many as possible of those in the last year of life on the register. If that was achieved, it is estimated the register would eventually hold information on between 3-4,000 patients.

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Case study 8

Sharing care plans and information across partners through Co-ordinate My Care and NHS 111

Staff at the Royal Marsden Hospital have worked with the DH and other local partners to develop Coordinate My Care (CMC) – a clinical service for sharing care plans and information across partners that supports individuals to die in their preferred place of death (PPD).

CMC uses a dynamic patient information flow approach to share care plans and information with reporting facilities across all CMC partners. Explicit consent is sought from individuals nearing end of life that their care plans and information about them can be shared with relevant professionals.

Staff report that CMC is changing the culture of palliative care delivery: it encourages professionals to trust each other and share a single care plan agreed by the person and their family. CMC has a dynamic reporting tool providing detailed accurate reports allowing clinicians to share results and best practice, changing behaviour as we go along.

Individuals and carers are given a hard copy of their care plan now, but next year it is planned to enable them to access their care plans through a 'patient portal'.

The CMC is backed by training which covers:

- Consenting
- Identifying
- Having difficult conversations with individuals and families
- Developing anticipatory care plans with individuals
- Training acknowledges existing delivery models of palliative care, building on and enhancing local systems e.g. GSF

Performance data has shown huge improvements already: of 2,827 CMC records from 6 London boroughs, 673 people have died on CMC; 82% of CMC registrants with documented preferred place of death achieved their choice. CMC is fully integrated into the new NHS 111 service. London is rolling out NHS 111 pilots aligned with roll-out of Coordinate My Care system and by March 2013 NHS 111 and CMC will be live across the capital. This has potential to transform the service that individuals and carers receive, creating opportunities to build on the NHS 111 service offering CMC to a wider group of high risk, vulnerable callers.

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Resources and further information

- **National End of Life Care Programme resources on co-ordination of care**
- **National End of Life Care Programme's Commissioning person-centred end of life care toolkit**
- **Quick guide to identifying patients for supportive and palliative care, produced by Macmillan Cancer Support, NHS Camden and NHS Islington**

3.4   Step 4 – Delivery of high quality care in different settings

Individuals nearing the end of life will often receive treatment and care in a variety of settings, from 'home' (residential or care home, hospice, own home), to acute or community treatment settings, or other settings such as prisons and homeless accommodation.

Some IDTs will operate across a number of settings; in other cases, a team may operate within a particular setting, such a hospital or hospice, but the individual may be receiving other elements of care, e.g. for a co-existing long-term condition, in another setting. Others may be transferred to a home or hospice for their final days. Sometimes, the IDT responsible for the person's care may also change when they move settings.

Communication often falls down when someone is moving between settings and this is a point at which it can be very helpful to assign responsibility for co-ordinating the transfer to a named individual within the IDT(s). Effective systems are also vital to enable information to flow both into and out from the IDT; as well as the right electronic and paper systems, there needs to be a culture of collaboration with other teams and settings underpinned by protocols for storing and sharing information. Transport between settings (including use of ambulance services) may need to be considered. If essential equipment, or an escort or carer, needs to travel with the person, an urgent health professional booking may be needed instead of routine patient transport services.

A change in care settings can be disruptive for both the individual and carer; the impact of a transfer on both should be assessed as part of the decision-making process.

a) Issues for IDT members to consider:

■ Have the individual/carer been fully informed about why and where they are being transferred, and about what this means for their care?
■ Has the impact of the move on both the individual and carer been assessed?
■ Will responsibility for the individual move to a different team as a result of the change in setting and, if so, has this been communicated to them and their carers, and to any others involved in their care?
■ What information about this individual/carer does the destination organisation/health professional require in order to anticipate needs and provide the right care? This may include information on essential equipment, care preferences and advance decisions
■ Who within or outside the IDT is best placed to co-ordinate the transfer?

b) Issues for IDT managers to consider:

■ What documentation is needed to ensure that the person's preferences and wishes are communicated when they are transferred?
■ Which team will be responsible for the person if they change setting and how is this clarified and communicated to the person, carer and other professionals involved?
■ Do all IDT members understand the booking criteria for different forms of transfers?
■ Are there joint education/training opportunities that IDT members could participate in alongside staff from other settings/services, to promote mutual understanding of roles and encourage better communication?

Top tips

- Make use of 'patient-held' records or EPaCCS where available

- Ask the individual about their preferred place of care at each stage and record their preferences

- Recognise there may be fears of abandonment when an individual changes their care setting – be clear and honest about what care will be available both to reassure and to manage expectations

- Seek time alone with the carer to understand the impact of a change of setting on them and ask if they need any additional help

- Dictate transfer letters in the presence of the individual or carer and copy this to all those involved in care

- Provide a reliable point of contact

Top tips

- Make links – at organisational and individual level – between teams and CCGs and GPs so that they are aware of what services are currently available across settings

- Arrange for the key worker to visit the person in their current care setting as part of planning for the transfer; encourage professionals from the current setting to contact corresponding professionals in the new setting

- Be aware of the person's prognosis and be alert to changes in their condition that may suggest a change in care needs or preferences

- Find out if there is a community matron leading on EoLC in nursing homes in the locality.

Resources and further information

- ■ **National End of Life Care Programme resources on delivery of high quality services in different settings**
- ■ **Gold Standards Framework resources**
- ■ **National End of Life Care Programme's *Route to success* series**
- ■ **Cumbria and Lancashire End of Life Care Network's Six steps to success programme for care homes**

3.5   Step 5 – Care in the last days of life

A point comes when the person enters the dying phase. For some this may appear to happen suddenly and without warning; for others it may be a more gradual progression. In either case, the individual's needs and preferences – as well as their condition – can change rapidly in the last days of life and members of the IDT need to be able to identify these changes and respond promptly and effectively.

The IDT can be a valuable vehicle for identifying the cues and clues that suggest a person's situation is deteriorating and that death may be imminent; some AHPs, for example, may spend additional time with the individual as a result of the nature of their intervention, which can help them spot the signs that their needs are changing and should be reviewed.

Maintaining dignity, comfort and quality of life may become more important at this stage than crisis 'intervention'. IDT members often have an important role in helping ensure that the risks of intervening are assessed and understood as well as in challenging assumptions among other professionals about the individual's needs and preferences for care. A culture of team decision-making will help ensure that the right decisions and interventions are made in a timely manner.

It remains vital at this stage to continue to treat the individual and their carer as core members of the team: they need to be clear on what to expect, what to do in the event of an emergency (especially if the individual will be in a residential setting for their final days); and should be kept informed of developments in their condition, changes to care plans and so on. Decisions, for example not to treat or feed, can be extremely alarming and distressing for carers and the clinical rationale needs to be carefully discussed and explained.

The needs and preferences of carers may themselves change at this stage and members of the IDT need to be alert to this.

The care environment is also particularly important in the final phase. Unnecessary clutter, noisy cleaning and so on can intrude on a person's final few hours, especially on a busy ward. Those involved more peripherally in care, for example cleaning staff, therefore need to understand their own role in maintaining a dignified and comfortable environment for those nearing death; managers may have a particular role in this.

a) Issues for IDT members to consider:

- Does the individual – and their carer – know they are dying? Who else needs to be told (both professional and personal)?

- Is this intervention in keeping with the individual's needs and preferences? Could their needs and preferences have changed? What guidelines and other decision-support materials are available to help me rapidly to assess a person's changing status and recommend the appropriate intervention(s)?

- What role does the carer wish to play at this stage? What practical help and facilities might carers and family members need (e.g. if they plan to stay with a dying person overnight)?

- Are the person and carer's spiritual needs being attended to?

- Do the individual and carer know what to do in the event of an emergency? Have they been informed about changes to arrangements for care (including out of hours), and to who will be involved?

- Is there an 'exacerbation plan' and support in place, in case circumstances change?

- How often do I need to be in discussion with the individual/carer and other members of the team? (More than daily may be appropriate at this stage.)

- When making a referral, am I confident that my colleagues have access to the right resources and information on that individual/carer to meet their care needs rapidly? What is my role in passing on this information?

b) Issues for IDT managers to consider:

■ Is there a forum for regular (more than daily) discussion within the IDT about the needs and care of the individual and carer?

■ What provisions are needed to enable rapid access to services, information and specialist expertise 'out of hours'? This may include empowering members of the IDT to access specialist palliative care advice 24/7, without waiting for permission from a doctor.

■ What is the best way to ensure rapid/timely access to funding – social care funding systems can be slow; CHC to Continuing Health Care (CHC) is faster, but IDT members may need additional support/training to complete CHC paperwork.

■ Are ward managers and other non-clinical staff such as cleaners and porters aware of their role in maintaining an appropriate care environment for those nearing death?

■ What mechanisms are in place to support IDT members through traumatic episodes?

Top tips

- Keep the focus on co-ordinating care to minimise unnecessary intrusion and undesired interventions

- Help keep the care environment calm, quiet and clutter-free

- Avoid making assumptions about the individual (or carer's) needs and preferences, which may change at this stage. Ask "Is there anything you'd like us to do? Is there anything you'd like us to stop doing?"

- Be alert to the possibility of tension between the preferences of the individual and their carers

- Acknowledge the time limits and manage expectations about what can be done

Top tips

- Make use of Rapid Discharge Pathways where these are in place

- Be prepared both to recognise and to challenge decisions about whether or not to 'treat'; explain to the individual and carer the rationale behind decisions

- Stay in regular communication with other members of the team: ensure changes and interventions continue to be recorded and that all IDT members (including the GP) are kept abreast

- Hospital/hospice chaplaincy services can be a good source of spiritual support

- Don't assume that all your recommendations have been acted upon – go back and check

Ann's story

Ann had motor neurone disease and cognitive impairment and was deemed not to have capacity to make decisions for herself. As her end of life neared, her family and the interdisciplinary team treating her were concerned to ensure appropriate care choices could be made for Ann.

Case conferences were held with attendance from Ann's daughters, her consultant neurologist, palliative care consultant, GP team, palliative care nurse, district nurses, physio, OT, dietician and speech and language therapist. Best interest decisions were made at these meetings on alternative feeding, resuscitation, breathing management, positioning and manual handling.

As Ann's condition deteriorated these best interest decisions were regularly reviewed by the interdisciplinary team with the consultant.

As a result of this approach, Ann's family felt supported and listened to in decision-making. All members of the IDT were aware of the best interest decisions made and able to coordinate her care. By carrying out advanced planning for the future, it was also possible to avoid unnecessary hospital admissions and prevent crisis management.

Case study 10

Multidisciplinary team decision-making to enable rapid discharge home

The aim of Blackpool's rapid discharge pathway is to facilitate a safe, smooth and seamless transition of care from hospital to community for individuals with terminal illness who choose to be cared for in their preferred place of care for their last hours and days of life.

An audit of the case notes of 60 people who died at Blackpool Victoria Hospital in December 2009 were examined and found that the reasons for not discharging individuals to their preferred place of care were down to:

- Lack of identification by clinical teams that individuals were at the end of life
- Failure to instigate discussion with individuals and relatives about end of life care
- Lack of co-ordination in care planning by clinical teams.

A successful rapid discharge service has been offered by the Trust since November 2009 by the hospital discharge team. The service is initiated once a multidisciplinary team agree that:

- The person has an advanced, progressive medical condition
- Their condition is deteriorating
- All reversible causes for deterioration that could benefit from hospital treatment have been excluded
- Senior medical team (Consultant or Registrar) agree the above and the prognosis
- The person wishes to be discharged from hospital for end of life care.

The service provides two options for individuals at the end of life, based on the clinical assessment – a four hour discharge for those with hours/days to live, and a fast-track discharge for those with days/ weeks to live. The latter will see a discharge within 24 hours.

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Case study 11

A rapid discharge pathway to enable discharge home to die, from a tertiary referral hospital

The logistics of arranging a rapid discharge for a dying person from a tertiary cancer centre serving over 2 million population can seem to be an overwhelming challenge for staff. To address this, a multi professional working group based at The Clatterbridge Cancer Centre, a tertiary referral hospital, developed and implemented a Rapid Discharge Pathway for the dying person following close liaison with services and personnel across the Network.

A retrospective audit, completed over the pilot period, showed that the new procedure was effective: six of the seven requests from individuals at the end of life for a rapid discharge were successfully met; the last was cancelled due to a rapid deterioration in condition. The audit demonstrated the effectiveness of a procedure to ensure discharge medicines. Close working with the pharmacy department enabled a system to be developed where discharge medication could be dispensed within one hour and appropriate equipment was in place. There was also good communication with families and other healthcare professionals. Challenges included ensuring ambulance availability, communication across different health communities, and out of hours discharges. Staff report that multiprofessional involvement and shared ownership have been key to the success of this project; moreover, facilitating individual choice at the end of life through a complex process has produced significant job satisfaction for all involved.

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Case study 12

Family's Voice – giving relatives and carers a voice at the bedside

North Tees and Hartlepool Foundation Trust has started to introduce diaries to allow carers to voice their thoughts and evaluate the care of their loved ones at the end of life. The diaries have been made available to the family of patients supported by the Liverpool Care Pathway (LCP). They are encouraged to record their perceptions of care at the bedside and this information is then read by staff and acted upon where necessary. The aim is to foster greater collaboration.

The main objectives of the initiative, which is entitled Family's Voice and began in March 2011, are to involve carers more closely in the end of life care of their loved one and to empower them to deal with specific difficulties that might arise. Between March 2011 and February 2012, 561 patients at the hospital were supported by the LCP, of whom 35% were offered the diary. Just under three quarters of those who were given a diary completed it and over half made additional qualitative comments.

Those who completed the diary included 28 daughters, 18 sons, 8 wives, 3 husbands and 5 brothers.

Most comments were favourable although some specific concerns were raised – and addressed. A marking system was devised to assess the overall quality of care. The maximum score is 24; a score of under 20 is unsatisfactory practice. Themes include: Respect for privacy, negative staff services, positive staff services, suggestions for practice, negative communications, and pain control and comfort.

Comments included requests for more sedatives and pain relief and for more information about the next steps and bereavement care.

This is believed to be the first tool of its kind which gives carers an opportunity to record their perception of care at the bedside of a dying patient in 'real time' rather than retrospectively. It also means staff are able to respond to a patient's concern quickly. One unexpected benefit has been that families have used the diaries to write about their feelings and expectations and this appears to have helped them prepare for the inevitable death of their loved one. So far there have been no complaints about the end of life care of their relative from those who have used the Family's Voice, which is a further indication of its effect.

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Resources and further information

- ■ **National End of Life Care Programme resources on care in the last days of life**
- ■ **Liverpool Care Pathway**
- ■ **Marie Curie Cancer Care**

3.6   Step 6 – Care after death

Good end of life care does not stop at the point of death. For the carers left behind, this is the beginning of a new phase and finding their new 'role', now that they are no longer caring for a dying person, can require considerable adjustment. Grief may be intense and can be compounded by feelings of guilt if the death did not happen as planned; it may also fluctuate over time, resurging unexpectedly months or years later.

> **I remember our district nurse telling us that the second year of bereavement would be worse than the first. I couldn't quite believe it at the time, but it was so true of myself.**
>
> Carer

Members of the IDT frequently have a key role in supporting the family/carers following the death. However, if the team member is not part of a specialist palliative care team there may be practical or caseload demands that require them to step back and/or handover to other professionals who may not have been involved to date; here, clear communication is key so that family and carers know who they can contact for further support and don't have to 'start again' with a new professional.

Mortuary staff, undertakers and coroners are also part of the 'team' around the bereaved. Good communication between them and health and social care professionals and IDTs in end of life care help ensure that carers receive the support they need after the death, as well as enhancing understanding of each other's roles.

The IDT itself is also a valuable forum for debriefing to improve care, and for much-needed emotional and pastoral support for professionals and others following a difficult death.

> **I was determined to transport my daughter's body from the hospital where she had died back to our family home at the other side of the country but I ran into problems with local bureaucracy. Undertakers in the area near the hospital told me that in order to transfer across counties, my daughter's body would have to be embalmed – an idea which I found very distressing. Thankfully, my local undertakers were much more compassionate and sensitive, and instead arranged to transfer her using a refrigerated vehicle.**
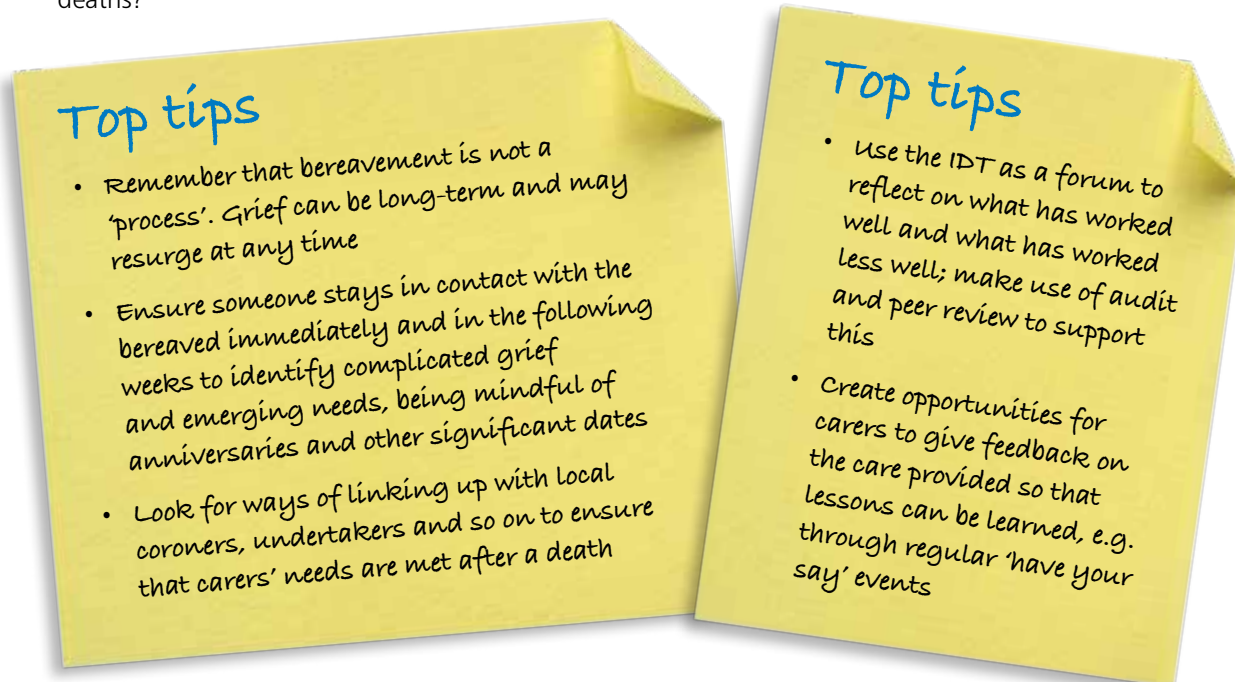>
> Roberta, mother and carer to Louise

a) Issues for IDT members to consider:

■ Are there vulnerable individuals (e.g. those with those with learning disabilities or dementia) or dependents such as children, whose needs must be considered? Is there a need to involve specialist support services?

■ Are there specific issues around spirituality and culture which need to be considered? Do any protocols apply?

■ Are there carer services available that can offer bereavement support or continue carer support post death?

■ What signs and cues might indicate that a carer is struggling with their grief? Who should I inform?

■ What are my own support needs following difficult deaths?

b) Issues for IDT managers to consider:

■ How can resources be utilised so that there is time for the carer/families to 'recover' following a death, rather than rushing to 'fill the bed'?

■ Whose responsibility will it be to support families immediately following a death, and to carry out scheduled 'follow-up' contact e.g. 6 months later? Within many teams, this will fall to a nurse.

■ What training, education, resources and protocols do staff need in issues around spirituality and culture?

■ What opportunities might be created within the team for debrief and mutual support following difficult deaths?

Top tips

- Remember that bereavement is not a 'process'. Grief can be long-term and may resurge at any time

- Ensure someone stays in contact with the bereaved immediately and in the following weeks to identify complicated grief and emerging needs, being mindful of anniversaries and other significant dates

- Look for ways of linking up with local coroners, undertakers and so on to ensure that carers' needs are met after a death

Top tips

- Use the IDT as a forum to reflect on what has worked well and what has worked less well; make use of audit and peer review to support this

- Create opportunities for carers to give feedback on the care provided so that lessons can be learned, e.g. through regular 'have your say' events

Case study 13

Reviewing significant events within the interdisciplinary team

Fishbone analysis is one model that has been used to enable interdisciplinary professionals in a clinical setting to review significant events.

Using simple fishbone analysis, the team works through steps such as communication, documentation, involvement of the family and so on, using post-it notes to describe what actually took place. They are then able to build a full picture of the care provided, review what happened, understand the implications of any key decisions taken and learn lessons from what went well and went less well.

This shared, open approach helps all team members to collectively and objectively review arrangements, while avoiding the tensions and defensiveness which can sometimes arise when reviewing significant events.

The fishbone technique can also be used to explore how teams are working together on an ongoing basis.

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Resources and further information

- ■ **National End of Life Care Programme resources on care after death**
- ■ **Admiral Nursing Services**
- ■ **Opening the spiritual gate e-learning programme**
- ■ **National End of Life Care Programme's What to do when someone dies**

Acknowledgements

www.endoflifecare.nhs.uk

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