

We need to talk about Palliative Care

NHS Tayside

1. Purpose

This report seeks to provide a summary of the feedback which has been received from colleagues in primary, community and acute healthcare settings in Tayside in response to questions posed on palliative and end of life care.

2. Background

The Scottish Government's Health and Sports Committee is conducting an inquiry into Palliative Care in Scotland. The Committee has issued a call for written views in relation to the inquiry remit which includes access to palliative care and initial conversations about palliative and end of life care. The SBH Palliative Care Project was asked to disseminate this request as widely as possible to all key stakeholders and collate the responses. There follows a summary of the views received.

3. Assessment

3.1 What has been your experience in terms of access to palliative and end of life care?

As a provider of specialist palliative care I have considered this over several years. Recent changes in remit and scope of specialist palliative care have been good. It is right to extend good care to all who have unmet needs and especially related to the moral imperative to ensure the end of human life is afforded dignity and respect. Moving from a cancer based, end of life care model to a need based model which extends to all diagnoses and is independent of prognosis has been right but has raised many unanswered questions. It is clear that traditional approaches in palliative care do not serve those with non-cancer diagnosis well on many occasions. Recognition of uncertainty in conditions such as heart failure, COPD and dementia is paramount and must inform advanced plans, models of interventions and acceptance of unclear/fluctuant access points between palliative care and acute/primary care. The move to extend palliative approach across all care descriptors has coincided with a focus on person-centred care and on occasions the distinction between "palliative care" and "care" have been blurred. Palliative care seems now to have a **mainstream remit but has retained slipstream resourcing**. Frameworks and clarity around these areas is much needed and specialist palliative care perhaps best considered as an additional layer of support that is provided in three specific ways:

- Direct service provision through specialist services – speaks into those situations where standard care has no answer. (The traditional "there is nothing more we can do"). This may apply in end of life situations or situations of "refractory symptoms".
- Supporting/enabling others through collaborative working and models. Supporting primary care, secondary care. Renal supportive care models. Heart failure collaborative models. Breathlessness clinics where oxygen

decisions are made – provide interventions targeted to reduce breathlessness experience as well.

- Clinical education and leadership – this is a role that permeates the first two. It needs resourced alongside service delivery so that it is robust and effective.

It is hard to know how to define the distinction of generalist palliative care and specialist palliative care in practical terms. In working in palliative care this seems to be best described at the point in which others need help in serious/advanced illness when there is a situation being faced that has no standard answer. As palliative care has extended into non-malignant disease this brings some lack of distinctions from what other specialities offer to attend to holistic outcomes – e.g. care of the elderly, renal teams, primary care, oncology.

We have also seen the remit of the specialist and generalist in palliative care extend into supportive care and symptom control for those who have intolerable situations that are not able to be resolved through standard care. Pain is one such area and we know in cancer pain around 80% of the time the WHO ladder is successful in controlling pain **but** this does not account for the need to ensure side effects of the treatments are minimal. In 2015, the options for achieving this balance of symptom control and minimal side effects are greatly improved and some expertise in this area helps. If we consider the statement, “The focus of palliative care is on preserving the quality of the person’s life so that their suffering is minimised but their experience of life is not” (Raising the Bar: a roadmap for the future of Palliative Care in Canada, 2010) to be true then there is a case for increased resourcing of direct specialist input and for resourcing indirect specialists roles in education in this area.

Access to palliative care depends on the referrers knowledge of the service and what is available. Often they are not sure at what point in an illness trajectory our involvement is appropriate which can be more problematic for people with non malignant disease due to uncertainty of illness.

It has taken many years for palliative and hospice care to be accepted and integrated into cancer care. In non malignant disease there is still much work to be done to enable integration of a palliative approach to care into medical models which dominate.

Specialist palliative care support is still very much focused around the needs of the oncology population rather than patients with non malignant disease or general frailty.

As a deliverer of care (in the community) I feel we are responsive we are responsive and when possible pro-active but a real issue can be trying to initiate personal care from social services.

Gaps in care (packages of care commonly restricted to 15 mins and maximum calls of 4 times a day) at home are offputting for some patients and families to

consider end of life care at home. Not being able to offer overnight sitters/services seven nights a week, as these are currently capped at 3 nights a week is another challenge for supporting end of life care at home. It has also been my observation that patients who have been given a palliative diagnosis in hospital are not then referred to the palliative care team whilst in hospital to offer them support, symptom management etc.

District nurses see this as core to their role however need support to keep people at home if looking after them over a period of time. Can pull out the stops and look after someone at end of life for a few days up to a week visiting 4 times daily however cannot maintain this service over longer periods – if social care unable to support quickly or support over night not available to help carers recharge their batteries the whole system fails and people are admitted which is often not their choice of care. Access to support services can be variable depending on where you live.

People and their families are given unrealistic promises of what community nursing can offer – 24 hour care rather than care over 24 hours. Marie Curie nurses when needed are limited in their availability and there are budget constraints from NHS.

Most GPs most would also see this as core business but are now getting so stretched with demands from acute care QOF and difficulty recruiting staff that many cannot visit palliative and end of life people like they could in the past.

Do people really have a choice? Hospice doesn't always have beds, acute care often does not see this as their role any more however that is where many people go when there is no flexible community service.

People in care homes will land in acute care if care home staff cannot cope – they can usually manage end of life care very well but need someone to support and signpost.

Palliative care specialists should be supporting colleagues who look after patients in their preferred place of care – which is usually at home, or in a care home. Palliative care in care homes is where many resources should be focussed.

3.2 How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?

This is challenging to try and fit existent models of end of life care to all condition types. The distinction between more predictable, progressive conditions (many cancers, often pulmonary fibrosis, MND, dialysis withdrawal when no renal function) and unpredictable conditions (majority of non-malignant diseases, especially COPD, dementia and heart failure. Now increasingly some cancers as they move to chronic conditions). The first place to start is to be clear that models of care will look different even if aimed for outcomes of dignity, comfort and reduced suffering are the same. Increasing training in palliative care and specifically end of life care for all specialities, nursing teams and community care is key. Evolving models of specialist input

need invested in, researched and tested. Fellowships in palliative care may help condition specific models to increase. We need to avoid the thought that “equity” means “equal” in terms of what models look like.

Improve training in palliative care for all health and social care professionals – the vast majority of people dying are not cared for by specialist pall care services and we need to train health care staff properly to do this skilled and satisfying part of their job.

It is still much more common for us to be referred patients with cancer than other diagnoses suggesting that there continues to be inequality in access for patients with a non-malignant diagnosis.

District Nurses are often not aware of the care needs of end stage cardiac patients, as they have little input. Need better awareness and education about recognising palliative care needs in patients with non malignant disease eg use of the SPICT tool.

Better collaboration and joint working between hospital based consultants, palliative care and primary care/GPs to improve continuity of care and communication. For example representation from palliative care in MDTs, ward rounds (eg care of the elderly) and community settings (nursing homes).

Raising awareness within primary & secondary care and ensure adequate resources to meet the demand especially for the community teams and specialist nurses. Transforming District Nursing in the community will help to facilitate equitable services across Tayside.

More local resources to support the needs of palliative care patients, especially in rural locations eg satellite clinics, community beds close to home, dedicated social care provision.

Many patients express a wish to die at home but this is often not possible because there is not enough resource in the community. There needs to more investment in social care services and outreach palliative care 24 hours a day to make this a ‘real’ choice for patients. Must also be recognised that for some patients admission to hospital for management of potentially treatable causes of their illness is appropriate – they should not be disadvantaged from access to Out of Hours or acute services.

It should be equitable but staffing levels in the community can make it challenging.

Services should be flexible and be able to work across traditional boundaries, for example going into nursing homes to help support.

There is a need to have more accountability, scrutiny and reporting mechanisms in place. Need peer review and adult inspections to achieve baseline measures and identify improvements.

Implementation of palliative care standards across hospital and community – all staff working within the same standards.

3.3 Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?

Acute care settings need more focus due to the volume of people who die. The 20:20 vision has not described a clear vision for those in whom hospital admission is unavoidable and who go onto die in hospital. How do we ensure home is achieved for those who wish to die at home when possible **and that** hospitals can also achieve deaths that have elements of what “home” is when the person cannot physically relocate ie. surrounded by loved ones, connections to meaningful memories and thoughts/emotions, privacy, peace, some elements of control etc.

Models of care being considered for disease conditions with more subtlety and recognition of the well established disease trajectories.

Care input at night in peoples’ homes attending to loneliness, fear and uncontrolled symptoms.

Clinicians need to be able to recognise when someone is approaching the end of life. Training needs to be available to support this and so ensure timely access to palliative care.

Raise awareness of specialist palliative care services and what the service can offer with patients and professionals.

Enhanced support at home including access to specialist review providing support for primary care teams/GPs. Quicker access to social care and equipment for people being discharged home from hospital to die.

Access to social care appears to be easier if the patient is being discharged from hospital.

Timely, responsive and flexible care out of hours provided by staff with the appropriate skills. More Marie Curie /Night Sitting Services to support carers. Access to GPs in the rural areas.

3.4 When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?

The framing of this question fits a condition with predictable progression more than chronic conditions with increased risk of death. In some ways it may be better to remove the term palliative care from this area and talk to people about future wishes in terms of care, social goals, maintaining autonomy (power of attorney, wills) and limits of interventions. This kind of discussion seems to cross the areas of social and community care until there is a specific health related event that can act as a clear trigger for considering mortality. It is useful to have expectation of clear descriptions of conditions that are chronic but incurable. These must recognise uncertainty and be sensitive. Avoid at all costs a tick box approach to this or a one size fits all. At best opportunities to consider these topics can be given but it should not be forced upon people to make decisions.

There is no formulaic answer to this as it will be different for each patient. However, the patient needs to actually know what is going on in terms of discussions about prognosis and sensitive exploration of patient wishes about this and planning for the future. These conversations take considerable time, and this time needs to be found.

In general terms discussions should be initiated by the team who know the patient and their family best (GP/DN, Hospital Consultant/Nurses), which may be in hospital or community setting or persons home. Patients and families should be made aware of role and scope of palliative care support available at the point when a life limiting, progressive disease is diagnosed so that they can access it as and when required depending on need.

It depends... certainly at diagnosis, when condition is changing, at times of transition. Always checking out and asking permission. However should be sensitive, timely and a partnership between patient, professional and those that matter to the individual. Should not be squashed into tight timeframe or started just before person is discharged as need opportunity to reflect and revisit.

This should take place at the right time for the individual person, taking into consideration their whole situation, including physical illness or disease trajectory, social, spiritual and psychological being. It is not necessarily any particular person or professions role but rather that the opportunity can be offered and negotiated at the right time, pace and with those who the person would like to be involved. This may be much earlier in someone's illness than health care professionals may identify. Also need to consider future capacity and engage early if capacity likely to be lost or change. Ask the person and offer future opportunity.

3.5 What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?

This follows on from the previous question adding that the content needs to be honest and recognising of uncertainty when present. It needs to give best guidance when time frames look clearer. It should be sensitive and iterative based on an evolved relationship of trust.

Taking the time to properly explain diagnosis, prognosis and what to expect to patients and their families ultimately saves time, panic, fear, unscheduled care and unwished for admissions. Ensuring that adequate time is given to this is the challenge.

Having time to sit and listen to people is the most important thing when discussing these issues. It also has to be someone that the person trusts- not necessarily someone who has known them for a long time (eg in hospital we discuss these issues often with people we have just met) but someone they feel they can speak openly with. The main challenge is probably getting health care professionals to have enough confidence to have these discussions with patients and relatives. Macmillan nurses are highly skilled in these

communications skills however community nurses need training to give them confidence in responding to cues and conversations before crisis.

When you have the correct information and the team (in its widest sense) need to communicate and record what conversations have taken place. It is a building up of information, not too much and at the right time with the opportunity to ask questions. Where you have effective well functioning teams. The key people involved should be aware of the facts and have a clear plan for possible scenarios and key contact details.

Focus on the person and what is important to them in their life. Relationship based care with a person who they feel they trust, who will listen and work collaboratively. Professionals need to be aware of their own attitudes to death and dying and to be comfortable to talk openly. The culture of thinking of death as failure rather than a good death as a good outcome still needs to be improved. Death is a normal outcome of life.

Palliative Register meetings can inform staff what discussions have taken place with the GP. The use of tools e.g. PPS, ACPs and Palliative Care Summary can also be helpful.

Communication of good practice

- Good practice can be shared at conferences, seminars, MDT meetings, DN meetings, through work shadowing and attending specific palliative care courses.
- Sharing experiences with newly qualified staff/ passing on skills to new staff.

Where do the challenges remain?

- Public perception, fear and distrust don't help (if previous bad experience).
- Remote and rural settings. Access to practical help/ personal care at times. Isolated individuals.
- Not having open frank discussions about condition, consequences of treatment both positive and negative.
- Lack of identification of palliative care needs.
- ACPs are only as up to date as the date they are developed – how do you ensure they are kept up to date and that everyone has access to the most up to date info?
- Electronic systems that do not “talk to each other”.
- Communication throughout the MDT and different parts of the same service can be challenging e.g. Day services and overnight; can be confusing who to contact and at what time.
- Challenges in ensuring staff involved in End of Life Care provision have the most up to date and evidence based training. Differences in the

experience of staff can be challenging especially when newly qualified and working a weekend or evening shift.

- All staff need to be proactive and practise anticipatory medicine and planning- very challenging if DN or GP in OOH is not familiar with the patient / family and has to deliver “bad news” if no previous discussion has been had or documented.

3.6 What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?

It is useful to have expectation of clear descriptions of conditions that are chronic but incurable. These must recognise uncertainty and be sensitive. Avoid at all costs a tick box approach to this or a one size fits all. At best opportunities to consider these topics can be given but it should not be forced upon people to make decisions.

ACP is in its infancy and it only makes sense if discussions can relate to real, achievable options. We need to ensure “care plans” are trust worthy before we expect too much of advanced care plans. ACPs for end of life must be similar to “birth plans” – an opportunity to record what you would like to achieve, values and goals but recognition that as events occur they may include things not anticipated or constraints that impact on what can be achieved.

Advance and anticipatory care plans should provide an opportunity to think ahead. It is a philosophy not a piece of paper and to be meaningful has to be person centred and focus on what is important to the person in their life and their care. Professionals need to be able to discuss and work with uncertainty and be prepared to also work with risk and to negotiate uncertainty. ACP is not a tablet of stone but rather an iterative conversation that is held over time and ideally within a relationship with health or social care providers.

Advanced plans need to have flexibility and an appreciation that what we are planning for is unpredictable and uncertain. What a patient *wants* and what they actually *need* may not be the same thing.

Anticipatory plans are a useful tool for guiding care, completing them can also be a prompt to discussing difficult topics and allowing the patient to state their wishes.

ACPs (when up to date and shared) can provide care providers with the exact wishes of the patient when he / she may not be able to communicate these wishes himself. ACP can steer the conversation into end of life care and expectations etc. Can avoid stressful situations when relatives/practitioners know what the patient wishes e.g. whether or not to be admitted to hospital. DNA CPR forms can also avoid stressful situations should a patient pass away at home.

ACPs take time to complete and should reflect timely discussions which support the wishes and needs of patients, which should be realistic and

achievable. They also need to be regularly revisited as the needs of patients can change.

ACPs provide individuals the opportunity to take some control of their illness. The uptake of ACPs is improving but the quality of the ACP discussion and their reviews is another matter.

How can their uptake be improved?

- Targeted projects, sharing of “what worked well” and “what didn’t work so well” patient stories, electronic training, basic awareness training that can be more in-depth for senior healthcare professionals.
- ACP should be part of core MDT training.
- Introduction of “ACP champions” in each MDT setting.
- Better awareness regarding “who’s job is it to complete”.
- Have to be mindful that not all patients wish to have the discussion/ cannot face discussing the future. This also needs to be documented to prevent other Professionals asking the same question and causing further distress.
- Having clear documentation & systems that allow the sharing of information across settings.
- Cultural change is very important. ACP leaflets have been very useful to stimulate discussions and make it normal to have them. Public health messages, poster campaigns more work like “good life good death good grief” has been undertaking. Taking message into communities and encouraging people to talk.
- Everyone going to a care home from hospital should have one offered as many of these people have had a life changing event that has taken them from home to care home setting.
- Having a senior nurse who has dedicated time to have gentle conversations with family and the person – as these conversations can be numerous over periods of time before an ACP is created and who has the confidence and skills to discuss DNACPR and complete the forms – trialled in care homes in Dundee and successful with a 98% uptake in one large care home.
- Currently anticipatory care plans do not inform our care of palliative patients. In order to be of use it should be a ‘live’ document accessible by all professionals involved, and maintained as the major document pertaining to the patients care and wishes. Uptake would need to be agreed by all professionals involved, and documentation agreed or amended to meet the agreed needs.

3.7 How should information about Palliative Care be made available to patients and their family during any initial discussions and how easily available is this information?

It is hard to answer this without a tight definition of what is meant by palliative care here. In general, sensitive discussions followed with some written information would be helpful. Contacts with services or key worker but all of this would need to be metered against illness journey point and persons own goals and wishes.

Information should be available in as many formats and routes as possible however handing someone a leaflet or directing them to a website does not suffice for a skilled, sensitive conversation.

Macmillan/Marie Curie provide information in written format and have websites where patients and their families can access information on a range of topics as well as via telephone helplines.

It is helpful for staff to know what services are available locally so they can share this with their patients.

More specialist nurses in GP surgeries (chronic disease clinics) which would enable more anticipatory care planning discussions with patients earlier in their disease trajectory.

An information leaflet for patients/families/carers is needed for people with severe and end stage dementia. There is little information in this context on eating and drinking/swallowing problems.

Need to ensure information is available in languages other than English and also in a format appropriate for the visually impaired.

3.8 What training and support is provided Health and Care staff on discussing Palliative Care with patients and families and are there any areas for improvement?

Communication skills are taught but there is a real need to increase experiential learning for all professionals.

It is difficult to release staff to attend training courses. eLearning although an alternative doesn't allow for discussion, reflection and sharing experience. Need to practice, rehearse and gain confidence in this and have good role models.

Education and training is provided through specialist palliative care services (SPCS) and covers a variety of topics for all grades of nursing and social care staff such as Sage & Thyme, anticipatory care planning and 'Courageous Conversations'.

Would be useful to focus on core medical/surgical/GP training stages, so that palliative care discussions can become ingrained in their practice and this would also help to forge professional links and deliver better joined up care.

There is less provision of undergraduate and postgrad medical training. This is an area which could be developed, but in a small speciality such as SPCS with large clinical commitments that is difficult to progress.

Having access to training is felt by primary and community nursing colleagues as very important, stating that regular in-house training / updates would be beneficial on all aspects of palliative care and for all levels of staff from healthcare assistant to GPs. However staff face challenges attending training due to their clinical commitments and difficulties with backfill to attend courses.

Uptake needs to be improved for staff and probably needs to be made part of mandatory training like BLS.

Acute care areas need more education regarding how to address end of life psychological needs in a busy environment.

There is a need for more training for non-cancer life limiting diseases.

3.9 How do Health and Care organisations ensure that the discussions about palliative and end of life care are taking place at the right time?

Some triggers may be useful but again need to be put in context. If we are talking about human care and human conversations then these will not fit a one size model. It is clear that responsibility and accountability for open and honest communication should be increased. Can measurement of this be enhanced as first step – record good and bad experiences of end of life care, ombudsman focus on this area in annual report and promote experiential learning in training.

Ensure early identification of people with palliative care needs and that a key person has some responsibility for offering the opportunity to discuss palliative care and person's needs. Holistic assessment is required. For people to be able to talk about the future they need to be informed and honest information about prognosis and future shared with them.

There is no one right time, just need to ensure that everyone is thinking about palliative care/end of life care as an issue which should ensure that discussions are had in a timely manner.

Healthcare professionals can ensure discussions take place at an appropriate time by using validated tools available to identify patients (SPICT, gold standards framework) and discussions about placing patients on palliative care registers within the community. Using audit (retrospective) to help gather valuable information/reflect on the patients journey, determine if & when Palliative Care discussions took place.

The development of locally available advanced communications skills courses would be a model for supporting clinicians to have these conversations.

3.10 What are the challenges in recording and documenting Palliative Care priorities and how well are those priorities communicated between different health and care providers?

It has been a good move to go from “palliative care summaries” to “Key Information Summaries” (KIS). The information in these systems overlap but to label as palliative sets up an unnecessary barrier and focus. It is also clear that such ACP systems should have clarity of focus so that information recorded about wishes at the end of life are not erroneously applied to admissions for intercurrent illness. Those with capacity and consciousness at the time of health events should be asked in realtime what their wishes are irrespective of the contents of pre-discussed KIS. Things change and people change their mind. So do professionals and assessments as real events unfold. Time remains part of the process in diagnosis and prognosis. ACP that is iterative and sensitive to change is key to avoiding clash between wishes and services provided.

Patients can change their minds regarding what their priorities are. The condition of patient may change and there could be conflicting priorities for care professionals and patient/family/carers.

Communication can be fragmented between different care providers (health and social care) and across care settings. Current eKIS system can only be generated/amended by GPs and cannot be created or updated by secondary care/hospice/social care staff in response to changes in the needs and wishes of patients. There is a need for a live electronic system which can be accessed by all health and social care providers so that decisions and discussions are effectively and efficiently communicated by everyone involved in care for example out of hours and at times of transition.

Delays in e-KIS updates whilst being inputted into the IT system, these are then delayed in uploading which has the potential to lead to adverse events in the community for end of life patients. It would be helpful if the ACP entered on Midas (community nursing IT system) then 'spoke' with the GP medical records eg Vision and uploaded the ACP from Midas automatically onto the GP records. Need integrated IT - currently there is a disconnect between these IT systems.

Different recording systems across different sites/areas mean that not all information is always accessible.

There is poor communication of DNACPR decisions in hospital to the community in discharge summaries, the original DNACPR copy doesn't follow the patient, documenting where the DNACPR is being held in the house on e-KIS, the reverse of the DNACPR form being left blank so Scottish Ambulance have no directions as to what to do with the patient should they die during their journey.....

Technology for Scottish Ambulance is improving to allow e-KIS access, nevertheless this is a 2 year project. An interim measure is required to ensure

that Scottish Ambulance consistently and accurately know about DNACPR for our palliative care patients at home.

4 Recommendations

The NHS Tayside Executive Team as asked to consider this feedback received from colleagues in the acute, primary and community care settings in respect of palliative and end of life care.

**SBH Palliative Care Project
NHS Tayside
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