

## We need to talk about Palliative Care

Jenny Reid

### Question 1:

I am an NHS Manager with >30 years experience of working within secondary care - primarily on Operational / Service Redesign issues in chronic disease and surgical specialties.

My Mum was diagnosed with Stage 4 Pancreatic Cancer in August 2014. She passed away in February 2015. I became her sole carer. I have walked every step of this journey and am deeply concerned about the current situation and our inability to deliver the care required.

The vision of Living and Dying Well is a good one. Patient centred care is at the heart of the process. Care to be delivered holistically. Planning and anticipatory prescribing are valuable. The needs of the Carer considered. All sounds positive. The vision and the reality of the care being provided within Grampian are two entirely different things, however. **The infrastructure and attitude to support the care required is simply not there.**

### Question 2:

Map of Care Pathway – I have seen a care pathway mapped out for Paediatrics but not for adult palliative patients. The map would not in itself ensure equity of access, however, it would diagrammatically demonstrate the care pathway (whether a patient is entering a palliative phase following a diagnosis of terminal cancer or following the deterioration and decline associated with COPD, heart failure, frail elderly etc.). It does not matter how or where you enter onto the pathway but the system, from that point, should be the same. Key benefits:

- Equity – care options that should be available for all
- A tool to enable and prompt conversations to happen e.g. when to commence / revisit care plans.
- Automatic electronic links to key information and national guidance
- Support decision making.
- Informing, prompting and enabling difficult conversations.
- A beneficial visual tool for patients and carers to clarify options and future considerations.

The map could be supplemented by other visual prompts to key stages – building blocks or a play on words, for example:

**P** – Patient centered – individualised care. Planning – ahead and recurringly. Patient safety.

**A** – Attitude (how would you want to be treated?) Assess and re-assess. Added value?

**T** – Timely information, at a pace that is suitable for the patient. Work as a Team.

**I** – Individualised. Information (honest, evidence based, check understanding and wishes).

**E** – Empathy. Efficient. Effective. Engagement.

**N** – Nursing – who, what, where, when – what are the options / based on needs assessment.

**T** – Training needs and provision for carers and all other practitioners.

**C** – Care pathway. Contacts. Communication. Choice. Compassion. Co-ordination.

**E** – Environment. Experience.

**N** – Named person to take the lead with dedicated time to co-ordinate and follow up care.

**T** – Traditional boundaries of care need to be crossed and managed. Appropriate transfer.

**E** – Expectations (Patient, Carer, Family, significant others?). Equity of Care.

**R** – Respite care. Reviewing the Plan. Responsive. Reliable.

**E** – Equipment (what is required to support patient and carer?). End of life – spiritual care?

**D** – Diagnosis - a life before and AFTER a diagnosis. Difficult discussions. Diagnosing dying. Dying with dignity.

### Question 3:

#### Care in the Community:

- Nursing care, in or out of hours via District Nurses, GMED, the Direct Delivery Teams, MacMillan or Marie Curie within Grampian is scarce to non-existent as is the presence of a GP. Approximately 1% of patients on a full time GPs register would be expected to die annually. This is a predictable workload and as such care should be planned and resourced accordingly.
- Equally the provision of Care via Social Care is an important aspect and again we need to be able to resource and recruit to these posts appropriately. We have within the NHS a duty to provide care “from cradle to grave”. Simply not providing care and to rely instead on family or friends or the voluntary sector to provide both the intensity and complexity of care required, is simply not good enough. We must resource this appropriately within Scotland. If we cannot recruit to these posts within their existing format, then we need to question why and determine what needs to be done to fill this gap.
- Consideration should also be given to Carers Leave – in a similar way to Maternity Leave – so that family / friends, who are being required to undertake this role, can do so without fear of losing their jobs or without

fear of losing their salary with no income to rely upon at such a critical time. For me, leaving my 85 year old Mum to die at home alone with no care provided was not an option. I had to take on the role to act as her Carer. There was no one else or no other option presented.

### Respite beds:

For the population of Aberdeen City, Roxburghe House has a bed compliment of 23 though not all bed spaces are appropriate for this type of care provision. 80% of patients are admitted for palliative care i.e. patients admitted for a specific purpose and then discharged home – the remaining 20% are expected to die during that admission. There are no other respite beds.

A patient who cannot move, eat or drink and who cannot function independently, cannot be made to feel unworthy of a bed and expected to be discharged back home with only, if available, two hours of Carer support being provided in a 24 hour period (this was the situation facing my Mum and I and the only option suggested. My Mum passed away <13hours after we had this conversation with her Consultant). Unless Scotland is to be regarded as a third world country, we simply have to do better. We have a duty to provide care.

This problem, as our elderly population continues to grow, will only become an increasingly difficult issue unless appropriately resourced and the infrastructure provided now.

Caring for the Carer – Where Care is provided via a friend or family member, we need to consider:

- Whether the family or individual can provide the level of care required, at each stage, as the disease progresses, and take cognisance of their own health, wellbeing and existing family or work commitments.
- What training needs exist to ensure that care is delivered safely for patient and carer?
- What equipment is required to support the carer and what training may be required to enable them to use this equipment?
- Who's who in the Team – does the carer know who to contact for certain aspects of care or support both in and out of hours.
- Managing medication – is the carer coping with this or do they need support or a process to ensure that medication is managed appropriately.
- At what point does it no longer become appropriate for this individual to undertake the role of sole carer? Please remember that a patient who is terminally ill has increasingly complex care needs. This questions the ability of the carer to provide care. Equally it is important that this individual needs to relinquish this role before it is too late – to have time

to simply be with the person that they love and care about before they die.

- Time needs to be allocated to the carer to discuss concerns and needs and potentially to prepare for the anticipated next stage. Carers often feel inhibited by the wishes of the patient not to challenge or ask questions depending upon the needs or wishes of the patient. However, what may be information overload for the patient may be essential for the carer to enable care to be provided. There needs to be an opportunity for the carer to talk openly and to have support.
- If the patient is admitted to hospital or a palliative care facility or a hospice, and if it is anticipated that the patient will return home, then the carer, if present, needs to be included in the communication loop during the in-patient stay and prior to discharge. This is essential if they are to be the one picking up on care at home when the patient is discharged. Continuity and clarity is essential. We should enable partnership working.
- Bereavement support and / or counselling should be considered for the Carer. Working with this level of intensity for so long whilst also losing the person you loved and cared for is hugely difficult. The intensity of the journey and the lack of support during the journey, however, means that there is no time for the Carer to begin to truly grieve. I cannot underestimate the impact on the Carer.

#### Question 4:

The conversation needs to start at the beginning when the patient receives a diagnosis which means that the only care option is Palliative. The important considerations for me are:

- The pace of the conversation is guided by the patient's level of understanding of their diagnosis and their inevitable decline.
- Practitioners need to be trained and have prompt questions available to them – though care should be taken that this does not simply become a task to be completed, rather like a tick box exercise.
- It is essential that the conversations are tackled sensitively and with empathy and at all times with the focus on the individual – what is their level of understanding? What are their hopes and fears and how can these be addressed? What are the most important considerations for them? What choices are available and how can their hopes best be supported?
- Conversations are not one-way – information to be given - but rather Practitioners must be able to LISTEN and INTERPRET so that the SOLUTION OF CARE DELIVERED REFLECTS PATIENT CHOICE AND PRIORITIES.

- Just as surely as the complexity of needs will alter as the disease progresses, it must be recognised that as our time draws near and the reality of the situation becomes clearer, it is possible that patients will change their mind about their priorities, wishes, where they wish to remain etc. That is ok and needs to be supported. Care plans and the delivery of care must be adaptable. Conversations iterative. Care individualised and supported. You only have one chance to get it right.

Who needs to be there? The patient and ideally at least one person who is important to them. I had not been asked to attend the appointment when my Mum was given the results of her CT Scan and informed of her diagnosis and that it was terminal. Thankfully, for both of us, I went to that appointment.

#### Question 5: (see also comments above under Question 4)

##### Leadership and co-ordination of care:

All too often we received mixed communication or actions were not followed through. It is essential that care is co-ordinated, recorded and followed up. **Dedicated time is essential to allow a practitioner to undertake this role.**

##### Seamless Care:

Care is frequently provided in the community by a variety of healthcare practitioners, individuals from the voluntary and social sectors as well as family or friends acting in the role of Carer. It is essential, for the benefit and safety of the patient that this multi-disciplinary group must **work seamlessly** and be **enabled to work as a virtual Team with effective communication and recording processes.**

##### Added value:

Every interface and interaction must count and add value. When resources are scarce, we cannot afford for highly skilled, trained and experienced practitioners to not be hands-on in terms of care provision. Frequently there was, for example, no district nurse to follow up on essential blood tests but the MacMillan Nurse had the ability to perform this function but was not permitted to do so owing to their job description. This needs to change. Each practitioner must work to their skill level and be enabled to provide a care function and progress the care needs as they arise during their visit. If we cannot change roles in this manner, then there needs to be better communication and follow-through to ensure what needs to be done, is actioned timeously

##### Recording Patients Questions:

My Mum asked the MacMillan Nurse (and others) several times how her disease was likely to progress or how her care needs may change but there was never an answer other than to say that what one patient may experience can be quite different to another patient's experience, therefore, it is best to just deal with the situation as and when things happen or change. Given that my Mum raised this question again and again, however, suggested, at least to

me, that this answer was not sufficient. She wanted to know what she could realistically expect to happen so as to prepare and consider her future and how this could be managed. Tackling and recording these questions more appropriately could have enabled her to have peace of mind as well as enabling more appropriate conversations about a declining state of health and how that could or would be managed – highlighting options, if these exist; training needs or managing expectations in the process.

#### Question 6:

##### Anticipatory Care Plan:

Having an individualised plan that is patient-focussed and holistic is essential to informing the care pathway and ensuring that, if we listen to, and record, the patient's changing needs and wishes, we get closer to delivering care that is right for every patient every time throughout the journey.

##### Patient Centered Care:

It is essential, however, to recognise that the needs and wishes of patient's, and their carers, will in all probability change over time as their disease progresses. The plan needs to reflect the complexity and intensity of care required. Planning needs to be done sensitively, with respect to the patient's wishes, capacity and needs and revisited on an iterative basis.

Again the pace of these conversations should be iterative and reflective of the individual – not driven by the system – even if this means that practitioners complete the Care Plan over a period of time and not seek to cover the whole plan in one consultation.

##### Holistic care:

I believe that the words holistic and patient centered rather trip off the tongue of practitioners but very few seem to really stop and think about the meaning of these words and put them into practice. Take one example of holistic care - my Mum had a deep sense of faith but no one picked up on this although it was recorded and mentioned when she was admitted to Roxburghe House and previously on the End of Life Care Plan. There needs to be a process, or a person with dedicated time to ensure that what is recorded is followed through quickly and efficiently. Spiritual / Pastoral care when someone is dying is important – if it is important to them – and there needs to be prompts in the system to ensure that what we record as being important is delivered.

A Map of the Care Pathway, as discussed above, could again help to prompt practitioners at key points in the journey. Someone being nominated as responsible for co-ordinating care would enable plans to be followed through and delivered.

#### Question 7:

My Mum received a terminal diagnosis but no one checked to see what her level of understanding of this diagnosis was nor was there any opportunity to discuss how this may evolve etc.

I was with my Mum at the time the diagnosis was given, however, it needs to be noted that the family / Carer is inhibited about asking for information, if the patient does not want to be told the information. The wishes / needs of the Carer / family, however, may well be different. As such information, and the opportunity to discuss the situation, individually and collectively is important if we are to appropriately meet the needs of both patient and carer.

Information is widely available on the internet. My family frequently “googled something”, however, you don’t know whether what you are looking at is reliable, evidence based, current and entirely applicable nor do you know if it reflects local practice and options.

It would be useful to have a range of recommended options to source reliable information related to the patient’s condition and care needs. Dependent upon the patient’s age, the internet is not always an option so a range of alternative media to provide information needs to be considered including internet, paper format, video format, face to face conversation and information exchange etc.

Such information could potentially be included in an individualised Carers or Patient’s Pack that could be tailored to their specific situation.

It may be important to include a word of caution. I quickly realised that our family around us saw each and every development in my Mum’s condition related entirely to her inevitable decline – their view being “supported” and “informed” by what they were researching on the internet. However, what became apparent, was that my Mum was more susceptible to, for example, chest infections, that were treatable and manageable. It is too easy to be led in a downward spiral by the information we can research on the internet today. It is important, therefore, for Practitioners to lead the way and guide patients and their Carer’s to reliable, localised, evidence-based and current information but equally to be able to ensure that they have a level of understanding about the situation that is appropriate.

#### Question 8:

Improvement?

The attitude of staff is key. Where do good examples exist? Roxburghe House – Nursing staff (Aberdeen) – get it right every time for every patient I suspect. Why? What is different in their training, recruitment, culture, team? Let’s take examples of good practice and replicate. Let’s take examples of bad or poor practice and resolve.

To deliver patient-centered care, you need to be able to feedback and train Practitioners about Patient / Carer experience. I am genuinely willing to use my experience in this regard and act as Patient Advocate reflecting upon our journey where this would add value to the process.

#### Question 9:

A Map of a Care Pathway would provide a visual prompt for Practitioners regarding the timing and content of palliative and end of life care discussions.

There needs to be a process to record and share information.

Are these discussions at the right pace, individualised for the patient or a tick box exercise? The only way I believe to accurately tell what is delivered against the vision is to measure and record patient and carer experience, to learn from the information recorded and to alter future behaviour, where necessary, accordingly. Plan, Do, Study, Act effectively.

Similarly staff should feel enabled (and have a mechanism) to feedback where they feel that care or planning was compromised and could be improved.

Measures of Quality:

Current measures are measures of quantity not quality. For example, how many palliative patients have a care plan, how many have DNACPR recorded, etc? These standards have produced nothing more than a tick box exercise. Not completed at a time and pace which is appropriate for the delivery of high quality patient care. The development of quality indicators based upon the key quality standards – timely, safe, effective care with cognisance of patient and carer experience is essential.

Question 10:

The use of technology should be considered to enable effective team-working, inform and record patient's needs and wishes and record agreed next steps.

**Jenny Reid**