

We need to talk about Palliative Care

Glasgow City Health and Social Care Partnership

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

- It is unclear what is meant by palliative and end of life care. The vast majority of palliative care is delivered by generalist staff who may not recognise that it is “palliative care” as they may simply see what they are providing as good care for people who happen to be dying.
- Referrals are received for individuals who may be termed as terminal or palliative or end of life. There is a need for a pathway, with consistent and clear guidance, to aid discussions and appropriateness of interventions.
- Usually access to palliative care services and end of life is fairly quick but this can depend on the diagnosis e.g. cancer versus long term conditions.
- Access is good when referrals come via District Nurses and Marie Curie.

See following models of good practice in GG&C:

Marie Curie Fast Track System

- The Marie Curie Fast track System, which was commissioned to meet the specific requirements of Reshaping Care for Older People, delivers a model of palliative nursing and social care clinically coordinated by Marie Curie Discharge Liaison Nurses providing fast access to Marie Curie health and personal care assistants to prevent admission and support discharge for palliative patients. The project, funded by Scottish Government and Marie Curie, commenced in North Glasgow and has now extended to all sectors in the city for a further three years. The model and its outcomes meet the current policy objectives for integration for partnership working, anticipatory care and palliative care.

Macmillan Pharmacy Service

- This award winning model contributes to more equitable access to community pharmacy palliative care and end of life care services in areas across Glasgow.

The model improves the way palliative care services are provided through improved support for all community pharmacies and training to support staff in all community pharmacies and improves care by promoting appropriate prescribing and dispensing of

palliative medicines and offers real potential to manage more people at home with palliative care needs rather than having them admitted to hospital in a crisis situation.

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?

- There is a need for greater access for non-cancer diagnosis and an understanding of what is palliative/end of life care. Everyone needs to understand the meaning and terminology of palliative care.
- Health professionals would need to recognise when patients are approaching end of life to be able to ensure that they get appropriate good care and effective symptom management. This would involve education to care settings that may not be experienced in delivering palliative care.
- There needs to be an increased awareness on how to access palliative and end of life care, and need could be coded as palliative in practices.
- There is a lack of awareness regarding people with learning difficulties and dementia

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

- Focus on the initial discussion and be clear regarding the information that has been provided to the individual.
- To ensure equity of care, priorities should be focussed on non-malignant disease. Time and resources are needed to make this equitable.
- Increase in access to overnight sitting services.
- Reduce carer exhaustion by providing more respite, improved provision of equipment especially in care settings to cope with patients, to cope with much needed population age planning. There is an unmet need here and more volunteers could offset this.
- Increase service reach to younger adults.
- 24/7 care at home and more Out of Hours Improved undergraduate teaching in DNS/ nurses / medics / Care home education.
- Undergraduate education should include more joint team working, more holistic education learning, to be more honest with patients and reflective in practice

- Staff valued and well trained with continual peer supervision.
 - Introduce “palliative champions”
 - Improve training when practising difficult conversations
- 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?**
- This should take place when the patient is diagnosed with a life limiting disease. This involves advance care planning by any health professional who knows the patient well e.g., GP, District Nurse. It should involve the patient and their family so that they too are aware of the patient’s wishes and should be discussed where the patient is most comfortable (e.g. home, surgery). Information should then be shared with all other professionals caring for the patient. For some disease pathways the discussions may be prolonged however this may need to be immediate for others.
- 5. What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?**
- The most difficult aspect is the communication between different services/levels of health care involved: At times services rely on the patient/family to provide this information. One of the challenges is that some patients are in denial but it is important to be open.
 - Using the tool, My Thinking Ahead and Making Plans (MTA&MP), booklet is useful in initiating these discussions. The patient and family can take time to think about their situation and then can revisit a week later to discuss more fully what has been decided by the patient. It is important to communicate all of this to A&E, acute services etc and to regularly revisit Anticipatory Care Planning (ACP) with the patient in case they have changed their mind about any decisions they may have made.
- 6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?**
- Anticipatory Care Plans are a good starting point and prompt staff to ask about palliative care. They need to be shared and initiated immediately.
 - There should be a standardised approach to ACP such as everyone using the same communication tool e.g. MTA&MP booklet.
 - Consideration should be given as to whether there should be a primary care worker for all individuals who have a palliative

diagnosis. The primary care worker could be professional or third sector but would require full information.

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?

- There needs to be a uniformed approach to delivery of terminal diagnosis. For all conditions secondary follow up and advice should be given. All patients should also be included on an accessible portal.
- This information is available in the Electronic Key Information Summary (EKIS) and Electronic Palliative Care Summary (EPCS) files.
- There should be face to face information provision with the main care giver e.g. GP, DN, Clinical Nurse Specialist (CNS).
- There is a lot of good information available on what specialist services and hospices provide and GPs or DNs can discuss this with the patient and family so that they are aware of what options are available to them.
- Improving the Cancer Journey (ICJ) is a new service the council launched on 5th February 2014. ICJ is a partnership between GCC, Macmillan Cancer Support, GG&CNHS, Glasgow Life, Cordia, Wheatley Group and Prostate Cancer UK. The Holistic Needs Assessment (HNA) service provides direct assistance, advice and information to cancer patients in Glasgow, their families and carers to ensure no one in Glasgow faces cancer alone. The ICJ project develops and delivers clear, seamless and accessible pathways of care that are accessed timeously and appropriately, across organisational and professional boundaries, based upon robust holistic assessment of need.
- Work is underway with the improving the Cancer journey Project to engage three GP practices in evaluating the benefit of using an ICJ practitioner “needs assessment” to inform annual cancer reviews within general practice while at the same time seeking to improve the quality of “end of treatment summaries” in collaboration with acute consultant staff.
- MTA& MP can help here as it helps to create the patients’ agenda.
- The majority of patients’ palliative care needs should be met by general staff.

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

- There is training; however there is a need to review what information is provided to the staff as they are often unsure what has been discussed with the patient.
- Staff should be encouraged to take ownership of their own continued learning development, for example use of LearnPro and e-learning.
- The Primary Care Palliative Care Teams provide a whole range of education to community nurses on communication skills, initiating difficult conversations, discussing DNACPR, BBN etc either ½ day, 1 day or 3 days, which are all available on the palliative care website.
- All health care staff should have the skills to be able to have difficult conversations with patients, which is where most of the support comes from.

There may be issues as to whether staff choose to use their skills. More could be done to assess attitudes/values.

- We need an environment where professionals have the surroundings /time to have these sorts of discussions.

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?

- Health professionals must recognise that the patient may be/ or is dying and then discuss this sensitively so that patients and families are prepared for what is going to happen. Currently this approach can be ad hoc and can be dependent on the underlying condition rather than progression of disease.
- The number of ACPs/ eKIS are monitored to assist in ensuring that that these discussions do take place.
- Glasgow City Council is committed to delivering a care home for life through the Tomorrow's Residential and Day Care Services Programme. Care Homes have trained staff and facilities that allow people to remain in a GCC care home, if so desired, during illness and avoid unnecessary moves.
- A Palliative Care Policy is in place for day care services and training provided to enable staff to provide care and support to service users with palliative care needs.
- The integration and reorganisation of Health and Social Care should assist in jointly addressing improving communication and joint working.

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?

- Communication is always challenging. The initial pathway could be more defined to lessen some of the challenges and to ensure that priorities are discussed and conveyed to all relevant parties.
- Currently IT systems are not all compatible between care settings. It is also dependent on health professionals documenting and recording key information that patients tell them about their wishes e.g., "do not attempt cardiopulmonary resuscitation" (DNACPR,) ACP etc. and ensuring that this is shared with other health professionals.
- Time constraints on staff are always a factor in being able to do this.
- The use of MTA&MP helps to record the patients' views. GPs can then add this to KIS

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