

# Palliative & End of Life Care Plan 2018-2023

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Governance & reporting Process

1. The Scottish Government adopted the World Health Organisation (WHO) Definition of Palliative Care in its Strategic Framework for action.

"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

#### Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death:
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

#### WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

#### 2. Our Vision

- 2.1 The HSCP's strategic vision reflects the intentions of the Scottish Government's Strategic Framework for Action and the Scottish Partnership for Palliative Care. That is that by 2021, everyone in Glasgow who needs palliative care will have access to it regardless of age, diagnosis or circumstance and that the care provided will be safe, effective and personcentred.
- 2.2 Staff delivering care will be supported via learning and education opportunities to understand how best to make a significant difference to a person's wellbeing, even in the last months, weeks, days and hours of that person's life.
- 2.3 Glasgow will be a place where people die well, are supported throughout Bereavement. Communities and individuals are able to help each other through declining health, death, dying and bereavement.

#### 3. Key Aims

- 3.1 People and their families and carers have timely and focussed conversations with appropriately skilled professionals to plan their care and support toward the end of life. The National Anticipatory Care Plan will be used to support this process and capture people's needs and preferences.
  <a href="http://ihub.scot/anticipatory-care-planning-toolkit/">http://ihub.scot/anticipatory-care-planning-toolkit/</a>
- 3.2 The HSCP's Palliative Care Plan will not be used in isolation but as part of a suite of material aimed at engaging people in their care and improving quality of life and wellbeing. This includes for example some of the material in the Scottish Government's 3rd Dementia Strategy (<a href="http://www.gov.scot/Publications/2017/06/7735/downloads">http://www.gov.scot/Publications/2017/06/7735/downloads</a>), in Realising Realistic Medicine (<a href="http://www.gov.scot/Resource/0051/00514513.pdf">http://www.gov.scot/Publications/2017/06/7735/downloads</a>), in the Carers Act 2016 (<a href="http://www.legislation.gov.uk/asp/2016/9/contents/enacted">http://www.legislation.gov.uk/asp/2016/9/contents/enacted</a>) and in the HSCP's Carer Strategy.
- 3.3 The Palliative & End of Life Care Plan will align with the aims set out in the Scottish Government's Health & Social Care Delivery Plan (<a href="http://www.gov.scot/Resource/0051/00511950.pdf">http://www.gov.scot/Resource/0051/00511950.pdf</a>), in particular the aim that by 2021 "everyone who needs palliative care will get hospice, palliative or end of life care" and that "all who would benefit from a Key Information Summary (KIS) will receive one". That Plan also indicates that people will receive more sensitive end of life support that will aim to support them in the setting that they wish

### 4 Actions - "What will we do"

The HSCP will -

- Work with our staff and with partners to identify learning and education needs and will use the NES National Palliative Care Educational Framework "Enriching & Improving Experience" (<a href="http://elearning.scot.nhs.uk:8080/intralibrary/open\_virtual\_file\_path/i2564n4083939t/Palliative%20framework%20interactive\_p2.pdf">http://elearning.scot.nhs.uk:8080/intralibrary/open\_virtual\_file\_path/i2564n4083939t/Palliative%20framework%20interactive\_p2.pdf</a>) to achieve a consistent approach.
- 2. Task Locality Palliative Care groups with implementing the Plan and ensuring that Locality implementation reflects an understanding of specific population needs in relation to palliative and end of life care. Locality groups will use the EQIA that was completed during 2018-19 to guide local work plans and consider inequality issues and specific EQIAs when developing services. <a href="https://glasgowcity.hscp.scot/publication/eqia-palliative-and-end-life-care-plan">https://glasgowcity.hscp.scot/publication/eqia-palliative-and-end-life-care-plan</a>
- 3. Ensure that Locality groups are representative of a full range of partners, including e.g. Improving Cancer Journey (ICJ), Hospices, 3<sup>rd</sup> & Independent Sector Providers, Health & Social Care staff, Practice Development/Macmillan Facilitators and Carer Services/Organisations.
- 4. Ensure that the outputs and outcomes from Locality Palliative Care forums inform the HSCP's Palliative Care Steering Group and SMT and are shared with the wider palliative care community via the HSCP's website and the NHSGGC palliative care website.
- 5. Following the scoping work on Palliative Care services for Babies, Children and Young People during 2018-19, a work plan has been agreed and the Children's Services Core Leadership group will collaborate with Children's Hospice representatives, Paediatric/Acute hospital services and 3<sup>rd</sup> & independent sector providers to identify leads for each workstream. Those leads will link with Locality Palliative Care Implementation groups and palliative care leads in adult services, particularly around points of transition.
- 6. Ensure Locality Plans and HSCP strategic documents capture the main palliative care priorities identified by Locality Palliative care groups.
- 7. Be part of the wider Glasgow & Clyde Palliative Care Network which will provide a platform for shared learning.
- 8. Outline the pathways between general care and specialist palliative and end of life care and check that these are clearly communicated at a local level and understood by those requiring and those delivering services.

- On an ongoing basis, develop conversations with groups of health and social care providers, using the information gathered in our palliative care survey 2016-17, to establish key areas for improvement and use the Associate Improvement Advisor to support approaches that enhance care delivery.
- 10. Embed Anticipatory Care approaches, using National ACP documentation where appropriate but recognising that plans might be available in a variety of formats. Staff will use an ACP summary tool to capture the key elements of people's plans and pass those summaries to GPs to inform the key information summary (KIS).
- 11. Ensure that staff are equipped to facilitate conversations about death, dying and bereavement; including the potential benefits or side effects of various care and treatment options.
- 12. Work with the HSCP's Primary Care Strategy Group, with Locality Primary Care Implementation groups and with Cluster and Practice Quality Leads (CQLs & PQLs) to achieve maximum benefit from their "Expert Medical Generalist" and MDT Leadership skills, to enhance the quality of ACPs and increase the number of people with Key Information Summaries (KIS). Reference will be made to the direct enhanced service (DES) Palliative Care Scheme for GPs with a palliative care register <a href="https://www.sehd.scot.nhs.uk/pca/PCA2019(M)06.pdf">https://www.sehd.scot.nhs.uk/pca/PCA2019(M)06.pdf</a>
- 13. Continue to support the Primary Care Palliative Care Team in delivering Palliative and End of Life care training to Health and Social Care staff who work in community settings.
- 14. Establish, in collaboration with patients, carers and Carer Groups, an ongoing feedback mechanism that informs the HSCP about people's experience and areas where further development might be required. This might include e.g. feedback on the care provided or the impact on family/carer wellbeing. Validated tools will be used where possible.
- 15. Consider the psychosocial and health impact on staff who work with the very ill, the dying and the bereaved on a daily basis and explore ways of supporting those staff to alleviate stress and possible absence from work.
- 16. Improve access to information for people requiring palliative care and their carers and families. This will include online and physical resources and will cover medical/clinical issues as well as non-medical issues such as Power of Attorney and Financial Advice.

- 17. Work within Locality groups to ensure that service provision is equitable and consideration is given to identifying and engaging with "harder to reach" groups, including e.g. ethnic minorities, people with a learning disability and people in prison.
- 18. Work with Marie Curie and Prince and Princess of Wales hospices in the provision of care, using their specialist expertise to take forward new and innovative approaches to delivering palliative care in the community and avoiding admissions to hospital as appropriate. We will also work closely with other hospices, particularly St. Margaret's of Scotland (and their associated HSCP, West Dunbartonshire) who care for many Glasgow residents and provide nurse/carer education.
- 19. Continue to work with Macmillan Cancer support in delivering information, education and testing new developments, including work to improve practice in relation to anticipatory care and anticipatory care plans between 2019 and 2021.
- 20. Develop our relationship with secondary and tertiary specialist palliative care services to ensure effective and timely transitions between places of care with particular emphasis on the involvement of families and carers in planning care and the provision of appropriate patient information at the point of discharge.
- 21. Develop our relationship with the 3<sup>rd</sup> and independent sectors in the planning and delivery of effective and sustainable service provision
- 22. Continue to work with Scottish Government departments to share practice innovation and to refine reporting and feedback mechanisms to give greater clarity on the impact of good palliative care.
- 23. Consider the workforce and financial implications of meeting the increasing need for palliative and end of life care in community settings and work with partners to maximise resource utilisation while identifying future funding opportunities. This will need to link to the HSCP's Workforce Strategy and to the Scottish Government's National Health & Social Care Workforce Plan <a href="http://www.gov.scot/Publications/2017/06/1354/downloads">http://www.gov.scot/Publications/2017/06/1354/downloads</a>.
- 24. Review data sources and agree a suite of measures that can be used to determine the impact of the strategy over its 5 year lifespan. This will include provision for ongoing monitoring and development of measures.
- 25. Maximise the totality of financial and personnel resource deployed in the city in order to develop a coherent and connected approach to the provision of good palliative and end of life care. By doing do, reduce the number of people

- that die in acute hospital settings and reduce the number of days spent in hospital in the last 6 months of life.
- 26. Work in partnership with Equipu to monitor the provision of equipment to people with palliative care needs. This will include the identification of commonly used equipment, the planning of future provision and the review, on an ongoing basis, of service response, particularly to those who require items urgently.
- 27. Embrace advances in telecare and telehealth for people with palliative and end of life care needs to enhance monitoring and safety within the community environment.
- 28. Identify in the 3 Glasgow Localities, the best approach to involving carers, families and communities in the support of people requiring palliative and end of life care.
- 29. Ensure there is local clarity in relation to accessing Bereavement and Counselling services.

## **Appendix 1 - Structure (Governance & Reporting Process)**

Outline of Glasgow's delivery model and connection to other HSCP structures & wider

