NHS
South East
Clinical Delivery and Networks

Commissioning & Investment Framework for Palliative and End of Life Care

This live document has been co-produced during 2020-21 and will be tested with partners before the final framework is confirmed by the national Palliative and End of Life team.

Contents

Introduction

People of all ages who face progressive life-limiting illness, with or without comorbidities, require different levels of health and social care at different points on their illness pathway. Apart from care and treatment that is specific to their underlying condition(s), they are likely to have needs that are often referred to as palliative or end of life care (PEoLC), especially as they approach the last year(s) of their lives. Throughout the trajectory of their illness, sometimes episodically, sometimes for prolonged periods, they may require expert assessment, advice, care and support from professionals who specialise in palliative care. These professionals work as part of multidisciplinary teams providing the service directly to the person with need, and those important to them, and/or supporting other care teams to do so.

Classifying services to support commissioning processes

The classification of palliative and end of life key services into commissioning categories has the intended aim of simplifying the process of confirming commissioning responsibilities and as a result of that, progressing service transformation.

There are challenges in its application including:

- It is recognised that Clinical Commissioning Groups (CCGs) and local authority commissioners will have great variation in what they currently commission and for whom. This is especially the case for care provided by hospices.
- There is currently a hospice grant currently paid to eligible hospices which supports some of the costs of their core and specialist services.
- There are gaps in service provision which often do not meet minimum NICE guidelines or the national Ambitions Framework.
- Continuing Healthcare Fast Track and funding care on an individual basis and synergy with core commissioned PEoLC services.
- 2020-21 and 2021-22 will be a year of development including:
    - Collaborative working at regional and ICS/STP level
    - Development of PEoLC networks
    - Contracting and funding mechanisms are being tested
    - Service specifications are under development

Therefore, areas need to consider all the factors above when they look to implement the framework. The milestones they choose to reach, and the timescales will vary according to existing arrangements and services. The standardised approach will ultimately contribute to achieving consistency and fair access for all.

Funding sources

It is acknowledged that the process of developing services, funding and contracting arrangements over the next five years will be an incremental transition, but this framework aims to support that process. The model of networks holding delegated budgets will be tested during the development period of the next 5 years.

Predominant funding sources for **core and specialist services will be from the CCGs and local authorities**. This may be from single CCGs or from collaborative arrangements. Local authorities will fund some activities in the core activities such as those linked to respite, integrated budgets, personal budgets, social care or education. There is a need for partnership working between CCGs and Local Authorities to ensure mechanisms are in place for appropriate funding. As the arrangements can vary from place to place these haven’t been specified in this document.

Charitable funding is that raised by hospices and other Voluntary and Community Sector Enterprises (VCSE). These monies will fund those activities in the enhanced category.

Hospices also receive some funding from national sources for core and specialist services. Currently, there is no national adult hospice funding programme although

additional non-recurring funds were allocated to CCGs in 2019/20 for adult and children's palliative care and this covered NHS Trusts as well as hospices.

The current **children's hospice grant** arrangement is a scheme that supports hospices provide core, specialist and enhanced services for children and young people. This money is paid directly to hospices from NHS England/Improvement. This funding needs to be considered in the round of negotiations. The funding for the national children's hospice grant programme is being increased from £12m in 2019/20 to £25m a year by 2023/24. As the hospice grant scheme arrangements are confirmed for the next 4 years then parties will need to negotiate fair funding that reflects sustainable provision.

The **Covid-19 hospice funding** package to all voluntary sector hospices in 2020/21 is to purchase general inpatient and community services capacity and it is non-recurrent.

CCGs may have local funding and contracting arrangements in place with hospices. Many CCGs have also received monies through the NHS England & Improvement children's PEoLC services **match-funding scheme from 2020/21**. This 4-year scheme aims to support developments for palliative and end of life care services by matching pound for pound that spent by CCGs in palliative and end of life care services in all types of providers including NHS Trusts and private sector providers as well as hospices.

The summary of categories

Core Services
Funding Source: CCGs and Local Authorities
These form the majority of services required by people with life-limiting or life-threatening conditions. They are key activities that should be commissioned and funded by CCGs, local authorities or a combination of both.
Specialist Services
Funding Source: CCGs
Specialist palliative and end of life care is required for people (all ages) living with more complex and/or long-term conditions which are life-limiting or life-threatening. The needs of this group cannot be met by the capability of their core team alone. This care requires a workforce with specialist skills and experience. They should be commissioned and funded by CCGs, local authorities or a combination of both. These activities are not to be confused with *specialised* services as these are services commissioned by NHSE/I Specialised Commissioning. As at July 2020, no *specialised* services were identified as commissioned by NHSE/I Specialised Commissioning. Therefore, at present, all specialist services are commissioned and paid for by CCGs. The main components of specialist level palliative care include, but are not limited to: • in depth specialist knowledge (specialist consultant and specialist nursing services) to undertake assessment and management of physical, psychological and spiritual symptoms to reduce symptoms, suffering and distress; • supporting analysis of complex clinical decisions-making challenges where medical and personal interests are finely balanced by applying relevant ethical and legal reasoning alongside clinical assessment

- providing multidisciplinary specialist advice and support to the wider care team who is providing direct core level palliative care to the person.

Enhanced Services

Funding Source: Charitable and other non-NHS funding streams

These are services which provide support to patients with palliative and end of life care needs and in some cases their families which are neither health nor social care. They should be funded by charities and not commissioned by the NHS nor local authorities.

Note on Using the Framework

It is recognised that definitions and examples of activities in each of the categories is useful for both commissioners and providers. The following tables aim to provide more detail on what may be reasonable included in each category.

Those using this guidance may find it useful to note the following:

- **NHSE/I Specialised Commissioning activities** – these have not been identified by NHS England & Improvement Specialised Commissioning and therefore do not form part of this framework. If these activities become relevant, then subsequent guidance will be updated accordingly.
- This framework does not include **services which are outside of the scope** of PEoLC such as mental health referrals, patient transport services, social prescribing and others.
- The **statutory functions** of clinical supervision, safeguarding, etc. are considered to be as standard.
- Training and staff development is a responsibility of the providers but there is an expectation that all providers and CCGs work together to have a comprehensive and consistent plan for developing staff.
- Overheads for **staffing and non-specific equipment** including consumables will form part of service delivery costs and do not need to be specified separately. Equipment required to provide nursing and medical care for palliative and EoL care should be funded by NHS.
- Specific **outputs from services** such as advance care planning, referrals etc. do not need to be specified separately
- The term **'bed-based'** refers to *any* bed service i.e. hospital or hospice.
- The year 2020-21 is the first year that this guidance is shared with commissioners and providers. **Wider consultation with colleagues** implementing this guidance will be sought and the guidance may be updated at intervals in line with feedback and policy changes. Commissioners and providers are asked to ensure they are using the most recent version when planning service change in their area.

Note on Age

This commissioning & Investment Framework applies to people of all ages including children and young people. The term 'Children and young people' refers to everyone up

to their 18th birthday as specified by NICE Guidance (NG6). This includes the antenatal period up to young adults. There is acknowledgement that different services will have different acceptance criteria for age (for example, young people are able to access paediatric services in a range from their 16th to 19th birthday).

The recommendation is that all children's and young people's services use the definition of age as set in this framework (18th birthday) as a minimum standard but where appropriate they work towards implementing services, where appropriate, for those up to the age of 25 years. This is especially important when considering service users with learning disabilities and transition requirements.

The Children's Hospice grant scheme and the match-funding scheme use the 26th birthday as the cut off age for children and young people.

Adults are generally classed as 18 years of age and over, however some areas commission adult services from age 16 years and above.

Note on Non-routinely Funded Services

It is recognised that the activities listed in the categories below do not capture all of those that may be deemed as beneficial for PEoLC but are not routinely funded. Examples may include services for complex grief where needs can't be met be standard mental health services, specialist therapies or experimental medications.

These are non-routinely funded services and as such need a process for decision making locally. This may be through an Individual Funding Request process for case by case requests, or an area may agree pooled funding for a larger footprint to benefit from the approaches, usually following a business case proposal.

Core Activity Definitions

Core Activities Funded by CCGs and Local Authorities	**Definition and Detail**
Adult or Children's Community Nursing teams	Provision of home-based or outreach community nursing care to people with life-limiting and life-threatening conditions. Note: Community nursing may not be exclusively provided by NHS providers. They can be provided by: • NHS Community or acute providers • Hospital specialist outreach teams • Local Authority teams • Hospice at home teams provided by hospices directly deliver nursing care or provide additional out of hours support to local Community Nursing teams. It is recommended that all commissioned services within a geography aim for consistency
Condition-specific Consultants/ Paediatricians	Community or acute consultant services. • Community based Consultants/Paediatricians will be responsible for supporting the person's care at home, especially for children with long-term disabilities. They can enable the family/carer to access medical support on a 24-hour basis including receiving support from local community nursing teams, GPs and multi-disciplinary palliative care teams.

	• Acute Consultants/ Paediatricians will oversee in-patient care stays including complex symptom management and end of life care where appropriate. They may be specialists in specific conditions such as cancer or neurology.
Bed-based care	Any admission for PEoLC symptom management with any skilled and equipped provider
Home-based care	Any clinical care provided in a home or care home setting. This may include care for Discharge to Assess, Continuing Care, Continuing Healthcare and Fast Track pathways. This is inclusive of legal rights to Personal Health Budgets (PHBs) and Personal Assistants funded via PHBs.
Step Up or Down bed-based care	This may include: • Bridging care until next-step care in place • Simple symptom management • Training for self-management / carers • Any skilled and equipped provider who is CQC registered.
Physical Therapies	Commissioners should ensure there is access to the following services. These will not necessarily be specific to palliative or end of life care needs: • Physiotherapy • Occupational Therapy • Speech and Language Therapy • Dietitians • Orthotists
Medicines	Local arrangements should be made for prescribing and access to licensed drugs. These arrangements are usually made via a local CCG prescribing committee. Local policy should be made available to all providers and pharmacies.

Respite Care / Short Breaks	Simple care needs can be met by generic respite services without further training or equipment. In some instances, people with life-limiting or life-threatening conditions will wish to bring their own carers to short break and respite settings – for example, where they have a personal budget. Funding arrangements should be joint with local authorities.
Emotional and psychological support including bereavement support	• Simple assessment processes with referral pathways to other services such as Psychological and Mental Health services – assessment can be provided by any appropriately qualified health professionals. • Bereavement counselling - provided by qualified bereavement councillors or psychologists.
Identify, Case Management and Personalised Care and Support Planning	Any appropriate health worker to identify, case manage and agree a personalised care and support plan or advance care plan. Planning should be in place for both palliative and end of life care needs. Collaboration with other disease specialists will ensure a fully comprehensive plan meeting all the patient needs e.g. cancer or dementia MDT teams Planning for children and young people will also include, where applicable for age and need, Team Around the Child (TAC) MDT approaches and supporting young people to develop transition plans. These should help make sure they experience smooth transitions to adult palliative care services and care which is appropriate to their age and developmental stage.
Spiritual Care	An expert (with any or no religious beliefs) in religious, spiritual and or pastoral care for patients, families and staff. Chaplains also provide education and advice to organisations or trusts. They work to a nationally recognised code of conduct and a set of standards and competencies.
Family assessment	Assessment of family/carer health and wellbeing needs and actioning appropriate referrals (may include social care).

Continuing Healthcare/ Continuing Care	Any palliative or end of life care and support provided in a home or care home setting. This may include care for Discharge to Assess, Children and Young People's Continuing Care, Continuing Healthcare (CHC) and CHC Fast Track. This is inclusive of legal rights to Personal Health Budgets (PHBs) and the provision of Personal Assistants funded via PHB.

Specialist Activity Definitions:

Specialist Activities Funded by CCGs	**Definition**
Specialist Nursing	• Nurses with expertise in palliative care operating at band 6 and upwards (for children it must be paediatric palliative care) • 24/7 care and/or advice service • Can be provided in acute settings, in the community or hospices.
Consultants in Palliative Medicine	Consultants in Palliative Medicine: • may provide clinical leadership across a number of locality teams. • 24/7 specialist advice services • supported by paediatricians, consultants and GPs with a special interest in PEoLC • can be provided in acute settings, in the community or in hospices. In some circumstances, services may be led by other medical staff with considerable experience in palliative care who may not be on the specialist register or hold a CCT (Certificate of Completion of Training) in Palliative Medicine. This situation is likely to be historic and may be acceptable in local circumstances at present, however as future opportunity arises the appointment of a Consultant in Palliative Medicine should be made.
Specialist bed-based care	Admission for symptom management overseen by a specialist consultant and/or specialist nursing team AND specialist palliative care health care needs identified
Specialist Equipment	Home care equipment for continuing care needs OR for a specialist nursing service provision where specialist training is required to operate the equipment.
Specialist Medicines	May include but not exclusive to: • High cost drugs • Red listed medicines • Experimental medicines

	Local arrangements should be made for prescribing and access to off-licence drugs. These arrangements are usually made via a local CCG prescribing committee and should be clearly communicated to all relevant partners.
Specialist Multi-Disciplinary Team (MDT)	The specialist PEoLC care team should include at a minimum (see NICE Guidance): • a palliative care consultant • a nurse with expertise in palliative care • a pharmacist with expertise in palliative care • other experts who have experience in palliative and end of life care (for example in providing therapeutic, social, practical, emotional, psychological and spiritual support) The specialist MDT should meet regularly.
Specialist Respite / Short Breaks	• Respite care in an appropriate setting for highly complex or technology dependent people who may otherwise be excluded from local core services • May be planned or urgent • May take place in the person's home or in a setting outside of the home such as a hospital, long-term care facility or hospice.

Enhanced Activity Definitions:

Enhanced Activities Funded by Charities and other non-NHS funding streams	**Definition**
Complementary therapies	Any activity deemed appropriate locally but with exceptions for those therapies not recommended by NICE or is a contraindicated with any medication that is being taken. The exception is where complementary therapies are identified as part of a personalised care and support plan (PCSP) and are funded by a personal health budget (PHB).
Support groups	Recommended group provisions for: • Adults, C&YP, parents, siblings, partners and family members (as appropriate). • Provision of social and therapeutic groups.
Practical support in accessing housing or the benefits system	This may be advice and support from individual providers or signposting to direct VCSE services or via Social Prescribing Link workers.
Emotional and psychological support	This will include some bereavement services. Support will be provided by experienced workforce. This may include workers and volunteers who are trained but not qualified professionals.