hospice UK

TOWARDS EXCELLENCE SERIES

How rehabilitative is your hospice?

A benchmark for best practice

The following checklist provides you with the opportunity to benchmark how rehabilitative your hospice is – to identify areas for development and to capture progress as you develop your Rehabilitative Palliative Care into the future.

St Joseph's Hospice

StChristopher's

Burdett Trust for Nursing

Name of Hospice or Palliative Care Centre: _____

Date: _____

Person-centred Goal Setting

Multidisciplinary support is focused around person-centred goals for each patient

- ☐ All holistic assessments, undertaken by any palliative care professional, in all settings, include a global question to explicitly identify a patient's goals and priorities. These may include:
  - » What is important for you to do in the next few weeks/few months/short while?
  - » What are your best hopes for ... this admission/the next few months?
- ☐ Together the patient, family and multidisciplinary team formulate an 'action and coping plan' to support achievement of the goal.
- ☐ Goals and action/coping plan are explicitly documented in patients' notes.
- ☐ For hospice inpatients, patients' goals are displayed in their rooms (with patients' consent).
- ☐ Input of all the multidisciplinary palliative care team is tailored to best support each patient's personal goal.
- ☐ Multidisciplinary team meetings and ward round discussions are contextualised around each patient's personal goals.
- ☐ Patient goals are appraised and feedback is given – this allows for acknowledgement and celebration of achievements or for reflection and reframing of goals where a patient's circumstances have changed and the goals are no longer a priority for them or no longer realistic.
- ☐ Where goals have been achieved, new goals are established.

Score: ____ **/8**

'Parallel planning' is used to introduce 'uncertainty' and actively plan for several possible outcomes

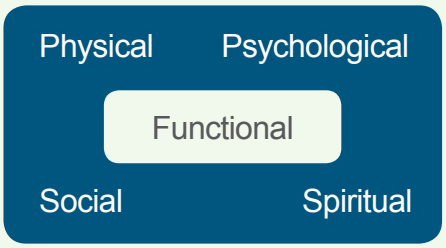
- ☐ Multidisciplinary team members actively introduce 'uncertainty' into goal setting discussions or at times where foreseeable change lies ahead. This may include a dialogue about 'hoping for the best and planning for the worst'.
- ☐ Action and coping plans are made for more than one course of action at the same time to support patients and families to anticipate and proactively plan for a change in their condition and avert crisis.

Score: ____ **/2**

Total score for 'Person-centred Goal Setting': ____ **/10**

Focus on Function

Functional assessment is established as a core component of palliative care holistic assessment



- ☐ Functional assessment is routinely incorporated as a core component of all palliative care holistic assessments.
- ☐ Functional difficulties are proactively screened for at first contact and regular follow up assessments by asking: Are you having any difficulty with moving around or managing your day to day activities?
- ☐ Where a functional difficulty is identified further assessment is required to establish:
  - » specific details of how function is being affected (including impact of symptoms)
  - » how this differs from the patient's normal baseline level of function
  - » time period over which the patient's function has been affected and how quickly it is deteriorating.
- ☐ Recognised, validated outcome measures which address function, such as Australian Karnofsky Performanace Status, Integrated Palliative Care Outcome Scale and Barthel Index, are routinely incorporated into palliative care assessment.
- ☐ All members of the multidisciplinary team are trained in undertaking a functional assessment. This includes:
  - » asking appropriate assessment questions and interpreting significance of answers
  - » where patients are able, routinely undertaking an objective assessment of function – this can be observing a patient's mobility when they let you into their property or asking a patient to stand from their chair and walk across the room
  - » initiating appropriate and timely actions in response to functional assessment findings.
- ☐ Screening of nutritional function is routinely incorporated as a core component of all palliative care holistic assessments.

Score: ☐ /6

Function is explicitly documented in patients' notes

- ☐ Functional assessment is explicitly documented in assessment at transition points between services (first contact assessment, inpatient admissions) or where a change in functioning is recognised.
- ☐ Functional ability, activity and participation for each patient is routinely documented by nursing and healthcare assistant staff over every inpatient shift.
- ☐ Functional status and any changes over admission are explicitly noted in patients' discharge summary.

Score: ☐ /3

Symptom control is routinely contextualised in relation to patients' function

- ☐ Assessment of symptoms is undertaken together with functional assessment (see page 21).
- ☐ Improvements in symptom control take into account both reduction in patients' symptoms and improved ability to function.
- ☐ Symptom control goes beyond control of symptoms at rest with the aim of achieving effective symptom control when the patient is optimally functioning (in line with their personal goals).
- ☐ Where functional compromise is identified, proactive referrals are made to allied health professionals to support patients' maintenance of function and prevent avoidable deterioration alongside symptom management, rather than waiting to the point where symptom control has been achieved.

Score: ☐ /4

Proactive early referrals are made to allied health professionals for specialist rehabilitation input

- ☐ Patients are offered referral to physiotherapy, occupational therapy, speech and language therapy and dietetics at the point where early functional decline is first proactively screened for and recognised.
- ☐ Referral to physiotherapy at early stage of mobility compromise (patient mentions feeling a bit unsteady when walking to local shop) rather than waiting until marked deterioration in mobility (patient is unable to walk to local shop following recent fall).
- ☐ Referral to occupational therapy at early stage when ADLs are beginning to be compromised or for proactive discharge planning (patient mentions difficulty preparing own meals), rather than waiting until patient is struggling to manage ADLs (patient requires social carer twice daily to support meal preparation).
- ☐ Referral to dietitian at early stage when appetite has changed rather than waiting until patient has lost significant weight.
- ☐ Referral to speech and language therapy at early stage of swallow (patient coughs following drinking fluids) or communication difficulty rather than waiting until patient has developed marked dysphagia (patient is admitted with an aspiration pneumonia) or is obviously struggling to communicate.

Score: ☐ /5

Total score for 'Focus on Function': ☐ /18

Enablement

Patients and families are supported to understand and expect that hospices provide enablement focused support which gives them maximum choice and participation

- ☐ Prior to admission to the hospice, patients and families are provided with information to help them prepare for their stay and know what to expect, emphasising our commitment to support them to maintain normality as much as possible.
- ☐ Patients and families understand that it is essential they bring in any items that will support them to continue to participate in their normal routines. This includes:
  - » day clothes
  - » shoes and slippers
  - » walking aids
  - » personal wheelchairs
  - » pressure cushions
  - » communication aids
  - » nutrition support devices or fluid thickening products.

Score: ☐ /2

Patients are supported to maintain their normal routines of daily life as closely as possible while in the hospice

- ☐ Upon admission assessment the team work with patients to understand their normal daily routine and consider how this can be best supported. This may include:
  - ☐ having a bath, shower or seated wash in the bathroom (to maintain this level of ADL functioning)
  - ☐ getting dressed into clothes everyday rather than pyjamas (to reduce the sick role experience)
  - ☐ spending time during the day out of bed and out of their room (to help reduce inactivity and prevent secondary problems such as pressure sores and chest infections, and to reduce boredom)
  - ☐ sitting out of bed for all meals (to support eating and safe swallowing)
  - ☐ taking meals in a communal environment on the ward or in the hospice restaurant with other patients and/or family members
  - ☐ having meals at the same times that they normally would
  - ☐ having maximum choice in meals (to suit their personal and cultural preferences and nutritional requirements)
  - ☐ maintaining the amount of walking they would be required to do at home, eg walking up to the toilet rather than using a commode beside the bed (to prevent loss of exercise tolerance and confidence)
  - ☐ going out from the hospice ward to the cafe, garden, communal spaces, local park or shops (to reduce social isolation and a narrowing of lived reality).

Score: ☐ /10

All members of the multidisciplinary palliative care team integrate principles of enablement in their daily practice and support of patients

- ☐ All members of the multidisciplinary team actively give patients the opportunity to make independent choices or do things for themselves before offering assistance.
- ☐ Where support is needed with physical activities, verbal prompts or tips to undertake the activity independently are offered before providing hands-on assistance.
- ☐ Where hands-on support is required with a physical task this is agreed in negotiation with the patient and provided with their consent, whenever possible.

  NB: Even patients who are in the last days of life can be supported through an enablement approach to care – this may simply involve supporting them to wash their own face or genitals if they are able to, or choosing which position is most comfortable.
- ☐ Nursing staff and assistants utilise motivational interviewing approaches to engage patients to participate in ADLs when they have capacity. For example, if a patient declines to get out of bed, the staff member explores the reasons why and identifies any factors which could be addressed.

Score: ☐ /4

Hospices create enabling environments

- ☐ Hospices have a range of enablement equipment to support patients' activity and independence. This includes:
  - » riser-recliner chairs
  - » adjustable height armchairs
  - » toilet aids – raised toilet seats, mowbrays
  - » environmental controls.
- ☐ Hospices create environments to support patients' normal routines:
  - » tea and coffee making facilities
  - » communal eating areas
  - » simulation spaces for ADLs such as kitchen tasks and bathing.

Score: ☐ /2

Hospices practice proactive discharge planning

Proactive discharge planning is important to guide patient, family and multidisciplinary team expectations for the admission and to enable forward planning (rather than waiting until symptom control is achieved). When practiced in combination with parallel planning (see page 18) this can be a constructive process even if discharge timeframes need to be extended, discharge location changed (eg to nursing home) or discharge cancelled (if patient becomes terminal). Proactive discharge planning gets people home earlier and supports people to achieve their preferred place of care and death. It also allows more efficient, cost-effective use of specialist palliative care beds.

- ☐ When patients are admitted for reasons other than terminal care, discharge plans are discussed with the patient and family upon admission to the hospice.
- ☐ Where discharge destination is home, and the patient's functional abilities have changed, early referral is made to an occupational therapist.
- ☐ In the days prior to discharge when a patient's symptoms are well controlled and their condition has stabilised, hospice support is tailored to mirror the package of care that the person will receive once home. For example, if a person will receive a four-times daily package of care, then nursing and healthcare assistants simulate four-times daily care in the hospice. If the person will receive significant support from family members at home, family are invited to actively engage with support at the hospice. This model helps patients and families actively prepare for the transition from hospice to home and builds coping and confidence. It also allows for staffing efficiencies on the inpatient unit so that nursing support can be focused on those with the greatest need.
- ☐ Following long inpatient admissions, graduated discharge is offered to support a successful and safe transition from a 24-hour support environment to home. This will differ for each patient but may involve a patient spending several hours at home with a healthcare assistant or family member, the patient then spending several hours at home alone, the patient spending a night at home alone – returning to the hospice following each graduation. While this may seem resource intensive it is more cost efficient than extended inpatient stays following an unsuccessful discharge. The main reason discharge fails relates to anxiety and lack of confidence on behalf of the patient and family. Graduated discharges can proactively prepare them for this adjustment.
- ☐ Hospices invest in the development of Independent Living Flats: a single bedroom flat which replicates a home environment as closely as possible in terms of equipment, meal preparation and care provision. This 'step down' facility provides a safe space for patients and families to 'trial' independent living, to optimise rehabilitation potential, to gain confidence and to enable transition from the maximally supportive ward environment to manage independently at home.

Score: ☐ **/5**

Patients in the community are offered models of palliative care support that optimise choice, normalcy and independence

- ☐ Patients are actively given the opportunity to attend outpatient services for support rather than the default option of home visits.
- ☐ Where patients are attending outpatient hospice services for a number of services, wherever possible these should be coordinated, including access to outpatient clinical nurse specialist clinics.

Score: ____ **/2**

Total score for 'Enablement': ____ **/25**

Self-management strategies are actively incorporated across all hospice support services

- ☐ Across all hospice settings, patients are empowered and encouraged to assertively voice their opinions, preferences and needs.
- ☐ Professional interactions with patients first seek to identify what they are managing well themselves and positively reinforce this, before exploring self-management strategies the patient and family could employ to address any difficulties currently being experienced.
- ☐ Patients are fully informed about the range of support options available to them including information support services, allied health professional rehabilitation, volunteer support and self-management programmes and are encouraged to self refer to these.
- ☐ Patients are routinely encouraged to undertake the elements of self-care they can manage themselves which are important to maintaining their sense of self. This may range from washing one's own genitals, making their own cup of tea through to going out independently.
- ☐ Assessments routinely include a question 'how much do you understand about your condition?' to ascertain patients' (and families') information needs.
- ☐ Patients and families are actively provided with information to learn about and better understand their condition in response to their information needs and wishes. This may include written information, verbal explanations or signposting to information support services.
- ☐ Patients are proactively referred to allied health professional services for nonpharmacological management of symptoms to learn strategies to self-manage breathlessness, fatigue, pain, lymphoedema – as an integrated component of best practice symptom management in line with latest evidence.
- ☐ All members of the multidisciplinary team have a clear understanding of nonpharmacological symptom management strategies and are competent to employ these in their daily practice, to support patients to self-manage their symptoms and reinforce positive coping behaviours.
- ☐ Patients are proactively offered the use of aids and adaptations which may enable them to manage daily tasks or activities without or with less assistance.
- ☐ Hospice offers self-management supportive group programmes, to equip patients and families with knowledge about their condition, strategies to self-manage their symptoms, and to share tips and coping strategies in a supportive social space with people in similar circumstances. These should include:
  - ☐ Breathlessness Management Programmes
  - ☐ Fatigue Management Programmes
  - ☐ Pain Management Programmes
  - ☐ Falls Prevention Programmes
- ☐ Hospice utilises the Patient Activation Measure to evaluate individuals' knowledge, skill and confidence for managing their health and healthcare as a recognised measure of self-management, engagement and empowerment.

Self-management strategies are actively incorporated across all hospice support services (Continued)

- ☐ Hospice utilises volunteers trained in rehabilitative and nonpharmacological symptom management to actively support patients to integrate self-management behaviours into their daily lives.

Score: ____ /16

Patients are supported to take informed and optimally managed risks

Supportive self-management involves giving the control back to the patient. Hospices may encounter situations where a patient's goals or choices predispose them to some element of risk. While we have a duty of care to protect patients from harm, if a patient's mental capacity is intact they have the right to make their own choices, even if these place them at risk. For example, a patient may choose to walk to the toilet independently even if they are at high risk of falling, a patient may choose to be discharged home even if there is a high risk of them failing to cope, a patient may choose to eat and drink even if there is a high risk that they will aspirate. Taking risks represents a way for people to exert choice and control over the things important to them. It also represents a way for patients to challenge their limitations and come to terms with losses of function or independence.

- ☐ Hospice teams provide patients and families with accurate information about the risks associated with their behaviours to enable them to make an informed choice.
- ☐ Hospice teams respect and honour patients' decisions even if they deem these risky.
- ☐ Hospice teams actively take steps to reduce and manage identified risks where possible – eg a graduated discharge may help a person explore and understand the risks in a safer, supportive way.
- ☐ Where risk is identified, this is documented in patients' notes with reference to mental capacity and informed decision making.

Score: ____ /4

Total score for 'Supported Self Management': ____ /20

Strategic Direction

Rehabilitative Palliative Care is an explicit priority in hospices' strategic direction

- ☐ The senior management team and hospice trustees understand and recognise the value of Rehabilitative Palliative Care at an individual, organisation and economic level.
- ☐ Rehabilitative Palliative Care is represented in the hospice's values and as a strategic priority in their strategic plans.
- ☐ The hospice has a robust operational plan to support the culture change and successful implementation of Rehabilitative Palliative Care across clinical services.
- ☐ The hospice has established a multidisciplinary Rehabilitative Palliative Care work group, including at least one member of the senior management team, to collaboratively take forward the enablement agenda.
- ☐ Senior managers actively engage commissioners and funders to resource Rehabilitative Palliative Care initiatives.
- ☐ The hospice fundraising and marketing teams understand Rehabilitative Palliative Care and promote hospice support which focuses on life and living to service users and the general public.

Total score for 'Strategic Direction': ☐ /6

Hospices invest in allied health professional expertise and leadership

- ☐ The hospice employs (or subcontracts) more allied health professional (AHP) disciplines – physiotherapy, occupational therapy, speech and language therapy and dietetics – to ensure patients have access to a comprehensive range of rehabilitation expertise in line with NICE guidance recommendations.
- ☐ The hospice capitalises on the unique contribution of AHPs as autonomous practitioners including:
  - ☐ AHP triage and first contact assessment of patients (physiotherapists possess robust skills in physical examination including functional, neurological and respiratory assessments. They are ideally placed to undertake comprehensive subjective and objective assessment of patients, contributing essential assessment skills that other professions may not possess).
  - ☐ AHPs lead on the management of patients receiving predominant input from hospice AHP services. This may be appropriate for patients whose primary needs relate to function, mobility or symptoms amenable to nonpharmacological symptom management in a stable phase of their illness. AHPs maintain close liaison with multidisciplinary colleagues to ensure robust governance structures and safe transfer of care to other professionals in response to patients' changing needs.
  - ☐ AHPs lead the multidisciplinary team in the shared management of patients admitted for palliative rehabilitation and key work these cases.
- ☐ AHPs are supported to lead the multidisciplinary Rehabilitative Palliative Care agenda across the hospice. This involves:
  - ☐ AHP resourcing sufficient to enable AHPs to work in leadership roles and ensure AHP clinical service needs are met
  - ☐ AHPs leadership roles are created with sufficient seniority to influence change across the organisation
  - ☐ AHPs are actively invited to engage with senior management and other leadership forums across the hospice.
- ☐ The hospice supports the development of extended scope practitioner AHP roles, eg AHP prescribers and AHP consultants.
- ☐ The hospice supports AHPs to actively participate in research to build the evidence base for palliative rehabilitation.
- ☐ The hospice actively seeks to attract AHPs to senior leadership roles – ensuring these are reviewed and where appropriate opened to AHPs when vacancies arise.

Total score for 'AHP Expertise and Leadership': ☐ **/12**

Education: Hospices educate and train staff to understand and competently deliver enablement-focused Rehabilitative Palliative Care

- ☐ AHPs work in partnership with multidisciplinary colleagues to raise the profile of Rehabilitative Palliative Care and actively lead/develop/contribute to rehabilitative education initiatives.
- ☐ All patient-facing staff have Rehabilitative Palliative Care responsibilities reflected in their job descriptions.
- ☐ All staff with Rehabilitative Palliative Care responsibilities in their job descriptions are required to attend practical mandatory training on enablement. This could include development of existing mandatory training programmes on moving and handling to be widened (under AHP leadership), to encompass moving and handling as one element of a comprehensive rehabilitative approach alongside:
  - ☐ principles and core elements of Rehabilitative Palliative Care
  - ☐ practice of enablement approaches with real patients (who share their perspectives, guide and provide feedback to staff)
  - ☐ clinical reasoning to inform how and when elements of Rehabilitative Palliative Care should be safely applied or tactfully withdrawn, including informed risk taking.
- ☐ Clinical staff provide evidence of Rehabilitative Palliative Care practice in their annual appraisal relevant to roles and responsibilities.
- ☐ Joint working is established between AHPs and nursing staff as routine practice on the inpatient unit, to model Rehabilitative Palliative Care approaches, learn from and support each other.
- ☐ Perceived or actual barriers to delivering Rehabilitative Palliative Care approaches across the multidisciplinary team are actively sought out and explored. Collective solutions are identified and learning is incorporated into enablement training.
- ☐ Healthcare assistants (or equivalent roles), who provide the majority of support to patients with ADLs, receive comprehensive training and support to ensure they are competent and confident to provide enablement support:
  - ☐ healthcare assistants have explicit responsibilities to provide enablement focused support in their job descriptions linked with competencies to reflect these
  - ☐ healthcare assistants spend a protected rotation working alongside the AHP team to learn rehabilitative skills, apply these in practice with patients in a supportive learning environment and have competencies signed off
  - ☐ nursing managers are responsible for ensuring healthcare assistants' competencies are upheld and actively integrated into daily practice.
- ☐ AHPs actively contribute to multidisciplinary journal clubs and other hospice wider education events to share current evidence and best practice on rehabilitation in palliative care.

Total score for 'Education': ☐ **/14**

Recruitment and Workforce Planning

Recruitment: Hospices proactively identify gaps in workforce skillset and undertake targeted recruitment to build rehabilitative experience and knowledge across multidisciplinary teams

- ☐ The hospice employs a range of AHPs – including physiotherapy, occupational therapy, speech and language therapy and dietetic – at senior levels (Band 7) to provide advanced practitioner expertise but also at more junior levels (Band 5 and 6) to attract and develop new generations of palliative care AHPs and provide career development opportunities.
- ☐ The hospice establishes new roles to actively integrate traditional healthcare assistant and rehabilitative roles. Organisations who have adopted this model have used the terms 'rehabilitative support', 'multidisciplinary', 'wellbeing' and 'enablement care' assistants.
- ☐ Recruitment to hospice nursing and 'enablement care' assistant roles target those with experience in stroke or elderly care rehabilitation to bring rehabilitative experience and competence to the team.
- ☐ AHPs are invited to be part of the interview panel.
- ☐ Recruitment to palliative care medical roles target geriatric and care of the elderly experience.
- ☐ The hospice discerningly recruits and trains volunteers to provide rehabilitative support to patients both in inpatient and community settings.

Total score for 'Recruitment and Workforce Planning': ☐ /6

How Rehabilitative is your Hospice?

Score Summary:

Person-centred Goal Setting:	☐ **/10**
Focus on Function:	☐ **/18**
Enablement:	☐ **/25**
Supported Self Management:	☐ **/20**
Strategic Direction:	☐ **/6**
AHP Expertise and Leadership:	☐ **/12**
Education:	☐ **/14**
Recruitment and Workforce Planning:	☐ **/6**
Total Rehabilitative Palliative Care Score:	☐ **/115**