Family Nursing & Home Care

Standard Operating Procedures

Children's Palliative Care Service

6 October 2021

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Contents

Introduction

Children and young people with life-threatening or life-limiting conditions and their families deserve support from many sources to maintain the best possible quality of life. Palliative care for these children and young people needs to commence from diagnosis or recognition of shortened life, and in some circumstances prior to diagnosis when certain conditions are suspected.

The publication "Together for Short Lives: The Guide to Children's Palliative Care" (2018) states that children and young people's palliative care embraces physical, emotional, social and spiritual elements. This holistic approach focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms throughout their lives, including end of life care and bereavement care for their families.

The Children's Community Nursing Team are commissioned to provide palliative care to the child or young person and their family, but work collaboratively with all relevant agencies across Jersey. The service will be evaluated annually from the perspective of the child/young person and their family, through the Measuring the Process of Care (MPOC) Survey.

Service delivery needs to enable children, young people and their families to live as full a life as possible. Family Nursing & Home Care (FNHC) recognises that families and carers are the experts in the care of their child/young person and strive to work in partnership with families ensuring a mutual respect and that the care is research and evidence-based, safe and appropriate.

These Standard Operating Procedures (SOPs) has been developed to guide the practice of staff working within the Community Children's Nursing Team (CCNT) for children and young people on the CCNT caseload that have been referred by a Consultant Paediatrician onto the Children's Palliative Care Pathway (CPCP). It provides a framework for the provision of safe, effective and holistic care, including respite support.

This SOP does not replace professional judgement, which should be used at all times.
A clear rationale for care provision should be presented to support all decision making, and appropriate assessment tools used.
Practice should be based on the best available evidence available.
Appropriate escalation and re-assessment should be initiated when individual care needs have this requirement.
When care is delegated to a non-registrant, the registered nurse remains accountable for the appropriateness of the delegation and the overall outcome of the delegated task.

SOP 1 Principles and Philosophy of Care

Purpose

This SOP outlines the principles and philosophy of care of the Children's Palliative Care Service (CPCS)

Scope

This SOP applies to all staff involved in the delivery of the CPCS

Core Requirements

All children and young people will have a full 'Holistic Needs Assessment' following admission and as a minimum annually to inform the plan of care. The focus of this is not only medical, but includes emotional, psycho-social, spiritual and cultural needs.

The child or young person and their family will be at the centre of all decision making. Every child/young person shall be treated with dignity and respect and shall be afforded privacy whatever the child's physical, intellectual ability or cultural background.

Parents shall be acknowledged as the primary carers and shall be centrally involved as part of the multi-disciplinary team in all care and decisions involving their child/young person.

Every child/young person shall be given the opportunity to participate in decisions affecting their care according to age and understanding.

Families will have a real choice: choice of place of care, choice of place of death, choice of emotional and bereavement support.

Information shall be provided for the parents and for the child/young person and siblings according to age and understanding. The need of other relatives including siblings shall also be addressed.

An honest and open approach shall be the basis of all communication which shall be sensitive and appropriate for age and understanding.

The family home shall remain the centre of caring, but short breaks provided in a variety of settings as appropriate.

Efforts shall be made to enable the child/young person to engage in all activities within their social/cultural/educational needs. Opportunities and quality of life should be maximised.

Every family shall be entitled to a named Grade 5 nurse and lead professional who will enable the family to build up and maintain an appropriate support system. The lead professional will be the Oncology Specialist Nurse if the diagnosis is oncology based, a social worker if there are safeguarding or respite/package-of-care needs, or a family partnership worker from the Child Development Team. The wider team will comprise of the required multi-disciplinary team with specialist and specific skills.

An active and dynamic approach to care will be provided from diagnosis or recognition through to discharge or death and in bereavement.

Children and young people should be free from distressing symptoms through anticipatory care and frequent assessment and re-assessment.

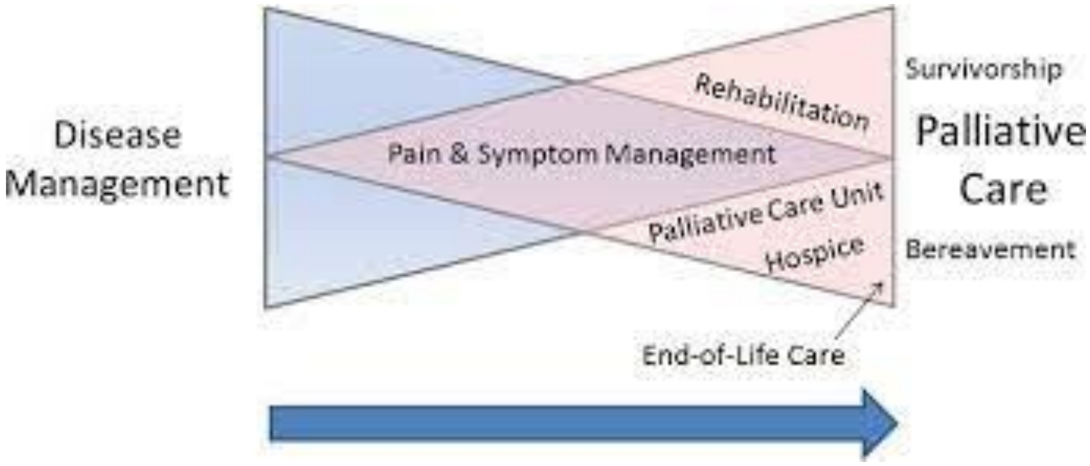
Parallel planning for disease management as represented in the 'bow-tie' model of care (Fig 1) will be implemented as required.

Every family shall have access to advice, support and information.

Where appropriate, planning for transition to adult services will commence and provision will be individual and tailored around the services available.

Care and support will be delivered in line with relevant FNHC policies and procedures and in particular, ensuring that any potential safeguarding issues are identified and reported appropriately.

Fig 1: The Bow-Tie Model of 21st Century Palliative Care (Hawley 2015)



SOP 2 Referrals; Sharing Significant News; Initial Assessment

Purpose

To ensure that the criteria to access the CPCS is equitable, with a clear and appropriate referral procedure and to ensure there is effective communication between the multi-disciplinary team, child/young person and family in relation to palliative care

Scope

This SOP applies to all staff involved in the delivery of the CPCS

Core Requirements

Referrals

Referrals of children and/or young people aged from 0-18 years will be made to the CCNT by a Consultant Paediatrician either locally or from the UK for support through the Children's Palliative Care Pathway

This will be a written referral using the appropriate CCNT referral form.

The diagnosis or condition will need to meet the criteria for referral as set out in the 'Together for Short Lives Categories of life-limiting and life threatening conditions' (Appendix 1).

This referral would activate Stages 1 and 2 of the Children's Palliative Care Pathway (Appendix 2).

Sharing Significant News

Once a child and/or young person has been identified for referral, the local Consultant Paediatrician will arrange contact and discussion with the named-nurse from the CCNT to brief and provide information. This should occur within two working days, as per the Standards.

Following this discussion, the named-nurse from the CCNT will be able to identify who the 'lead professional' will be and make contact with them directly or copy the referral to the senior practitioner within the Child Development Team for allocation. This should be achieved within two working days, as per the Standards. .

A meeting will then be set up with the Consultant Paediatrician, the named-nurse and the lead professional to meet with the family in an appropriate venue. Every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. The referral will be fully discussed.
This should take place within three working days, as per the Standards.

The family will be provided with any additional information they may need and be given contact details for the CCNT, named-nurse and lead professional if they do not already have this. A Children's Palliative Care Leaflet will be provided. Consent will be obtained to share information between professionals as required.
This should take place within five working days, as per the Standards.

Initial Assessment

The child and families demographics and details will be gathered. The Holistic Assessment Response Indicator (HARI) Tool (available on EMIS) will be completed to establish as to whether the initial assessment process needs to commence after one day, five days or ten working days.

The initial assessment will take place at the family home with the named-nurse and the lead professional within 1-10 days depending on the HARI score and need.
A blank Holistic Needs Assessment (available on Central Filing) on is used to capture the detail. If immediate needs or concerns are identified, appropriate actions, delegation or referrals may be required.

It may take several visits or liaisons with the multi-disciplinary team to complete the Holistic Needs Assessment. The lead professional will arrange a 'Team Around the Child' (TAC) meeting once this process had commenced, to discuss the assessment findings and create a plan of care known as a TAC Plan.

Once signed off, the TAC Plan will be circulated to the TAC team members and reviewed on an ongoing basis as required. This will be variable and could be every few weeks or six monthly dependent on the child and family's needs.

The Holistic Needs Assessment will be reassessed annually unless there is an identified trigger, such as:

- Subsequent Diagnosis
- Significant change in condition, treatment (including discharge from CPCS) or family circumstances
- Recognition of incurability
- Recognition of end of life (beginning of stage 3)
- Final stage of life
- At child / families request
- Recognized as required by 'Team Around The Child' member

SOP 3 Symptom Management and Advance Care Plans

Purpose

This SOP gives guidance to staff to ensure that all children or young people on the Children's Palliative Care Pathway will have a Symptom Management Plan (SMP) and an Advance Care Plan (ACP) in place.

Scope

This SOP applies to all staff involved in the delivery of the CPCS

Core Requirements

Symptom Management Plan (SMP)

Good symptom management planning has been shown to reduce the need for out of hours support as practitioners have considered in advance and prepared families and other carers how a child's symptoms may progress and have a plan in place to deal with them. This is particularly important if the child is cared for in the community.

Parents will be reassured that there is a 'next step' and their child should not 'suffer' due to symptoms that are out of control; professionals will be equally reassured that they have one agreed plan to follow.

Discussion of the SMP can be a very useful opportunity to prepare families for what may happen, particularly at the end-of-life, but it is important to stress that each child will not develop every symptom.

SMPs are individualised plans written specifically for each child hence creating one template that covers all potential situations is not possible (Goldman, Hain and Liben (2012).
Therefore, consideration needs to be given to the following:

- Explain the reasons for the symptoms and management strategies in simple terms and avoid medical jargon. Discuss 'The Child' as a whole
- Symptoms are never purely physical or purely psychological and all symptoms and treatments will have an impact
- The Holistic Needs Assessment and TAC Plan
- Consider causes other than the primary diagnosis and explore the impact of the symptom on the quality of life
- Review and re-assessment of all treatments – what has worked well previously? Correct the correctable as long as it is practical.
- Ensure that both pharmacological and non-pharmacological methods of treatment are considered

- For the plan to be most effective it will need to be used in all the settings the child frequents e.g. home, school, short break providers as well as other health providers.
- Careful consideration should be given to the wording of the plan ensuring that descriptions of care are accessible to all users including families.

Advance Care Plan (ACP)

An ACP is designed to communicate the health-care wishes of children who have chronic and life-limiting conditions. It sets out an agreed plan of care to be followed and provides a framework for both discussing and documenting the agreed wishes of a child/young person and his or her parents, ranging from simple 'wishes and hopes' during life through to when the child/young person develops potentially life-threatening complications of his or her condition.

Where a child/young person is considered to have capacity, their views should be considered in the decision-making. Capacity is related to specific decisions so a child/young person may have capacity for one decision and not another.

It is designed so that it could be used in all environments that the child encounters: home, hospital, school, hospice and respite care. It is also appropriate for use by the ambulance service.

An ACP can be used as a resuscitation plan and/or as an end-of-life care plan. It remains valid when parent(s) or next of kin cannot be contacted.

The process may involve several different discussions over a period of time as it is essential that all concerned in the decision-making process are allowed enough time for information to be given and understood, to consider, to ask questions and to express their opinion. Please refer to the Child and Young Person's Advance Care Plan (CYPACP) document.

As part of the information gathering process, the named nurse should capture the 'hopes and wishes' of the child/young person as this is likely to also inform the TAC Plan. The named nurse should support the named paediatrician in starting the conversations with the child/young person and their family, which will require regular review – especially if there has been a significant deterioration or change in the child/young person's condition. It should then be distributed to all involved within the child/young person's care.

SOP 4 End of Life Care

Purpose

This SOP gives guidance to staff to ensure that all children or young people on the Children's Palliative Care Pathway are cared for appropriately at End of Life.

Scope

This SOP applies to all staff involved in the delivery of the CPCS

Core Requirements

The Consultant Paediatrician – either locally or off-island – will identify that the child or young person has had a significant change in their condition and is now considered to be approaching the end of their life.

This notification would activate Stage 3 of the Children's Palliative Care Pathway (Appendix 2), acknowledging that the pathway approach to care should extend throughout the care journey and at the time of death and beyond.

This should include focus specifically on:
- Care before death
- Care at time of death
- Care after death
- Bereavement Support
- Staff support

Each child/young person and their family will require specific care tailored to their individual needs. The assessment process, planning, advance care planning and symptom management plans do not change at this stage of care, but will need frequent review and regular updates as required.

Medication based 'Symptom Management Plans' may well be provided by the Specialist Palliative Care Teams based in the UK at this stage, and liaison with them will be required as well as the local team. This could potentially be several times a day. The principles and philosophy of care as in Stages 1 and 2 of the pathway also remain the same.

The importance of appropriate, timely and co-ordinated systems of care provided to the family at this time cannot be underestimated. Spirituality, faith and cultural care are encompassed within this, and skilled and effective communication skills are central to providing quality care.

As recommended by NICE (2016), care planning at this time needs to involve anticipatory care and provision, and adaptations provided to education, play and respite.

Financial, material and technical support will need to re-assessed and frequently reviewed as the child/young person's condition deteriorates.

Once the 24 hour on-call support commences a clear rota of staff cover will be created. This will incorporate the changing of syringe driver medications if/when they are required to ensure that all cover is adequate.

SOP 5 Respite Care Provision

Purpose

This SOP sets out the process for provision of respite care by the Paediatric Palliative Care Worker (PPCW)

Scope

This SOP applies to all staff involved in the delivery of the CPCS

Core Requirements

All children/young people will have specific care plans which will be reviewed by the named-nurse and PPCW at frequent intervals.

A referral will be made to the PPCW from the child's lead nurse at any stage of the pathway support journey, discussing what sort of respite is required and any important information surrounding the child and family.

A joint visit with the nurse will be arranged to meet the family and discuss respite. The family may need home respite, sibling respite or respite in the form of community outings. Depending on the child, the number of additional home visits for them to get to know the PPCW will vary, however a minimum of three is suggested.

During the PPCW's first lone visit to the home, the PPCW will give the parents a consent form to sign, this will allow future respite in the home and in the community. The consent form will cover car journeys and bus journeys, however if swimming is an appropriate outing for the child, a separate consent form will need to be filled out.

Risk assessment will be required before going on any outings with the child, following the community risk assessment guide lines to ensure all the child's unique needs are met. The risk assessments will be different for each activity and each child as their needs will vary (Appendix 3).

The child's condition may change over time, meaning they may need more or less respite; if/when this happens the risk assessment will need to be redone in case there are any changes

Where respite is being provided in the family home, this will still need to be risk assessed, following the 'family home risk assessment' guidelines. This is to ensure that the child still receives the best care even though they are at home and will also allow the PPCW to familiarise themselves with the surroundings (Appendix 4)

SOP 6 Training and Staff Support

Purpose

To ensure that all staff working in children's palliative care have access to appropriate training, resources and support.

Scope

This SOP applies to all staff involved in the delivery of the CPCS

Core Requirements

Training and education will be made available by the Community Children's Nursing Team Lead Nurse for Children's Palliative Care for staff to support the development of knowledge and skills.

Training and education is available through on-line training websites for children's palliative and end-of-life care.

Supervision and support is available for staff which can be adapted to suit personal need.

References

Goldman, A; Hain, R. & Liben, S. (2012) *Oxford Textbook of Palliative Care for Children.* Oxford University Press

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National Institute for Health and Care Excellence (NICE) (2016) *NICE Guideline NG61: End of life care for infants, children and young people with life-limiting conditions: planning and management*. Available at Overview | End of life care for infants, children and young people with life-limiting conditions: planning and management | Guidance | NICE. Last accessed 9th September 2021

Together for Short Lives (2018) *A Guide to Children's Palliative Care.* Available at TfSL-A-Guide-to-Children's-Palliative-Care-Fourth-Edition-FINAL-SINGLE-PAGES.pdf. Last accessed 8th September 2021

Appendix 1 Categories of life-limiting and life threatening conditions

(Together for Short Lives 2018)

Together for Short Lives (2018) recognises that four broad groups of life-threatening and life-limiting conditions may be delineated. Categorisation is not easy and the examples used are not exclusive. Diagnosis is only part of the process; the spectrum of disease, severity of disease and subsequent complications as well as the needs of, and impact on the child and family need to be taken into account.

These four categories outline the four types of illness trajectory which will require children's palliative care provision. The categorisation is important for the purpose of planning and needs assessment. The categories demonstrate the range of conditions children have and show how children may benefit from palliative care, or elements of palliative care during their journey. The need for palliative care should always be assessed on an individual basis.

Category 1	Life-threatening conditions for which curative treatment may be feasible but can fail. Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. Examples: **cancer; irreversible organ failures of heart, liver, kidney**
Category 2	Conditions were premature death is inevitable. There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: **cystic fibrosis; Duchenne muscular dystrophy**
Category 3	Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years. Examples: **Batten disease; mucopolysaccharidoses**
Category 4	Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death. Examples: **severe cerebral palsy; multiple disabilities such as following brain or spinal cord injury; complex health care needs; high risk of an unpredictable life-threatening event or episode**

Appendix 2 Children's Palliative Care Pathway Standards and Goals

(Together for Short Lives 2018)

Pathway Standards	**Pathway Goals**
Standard 1 Every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided for the child and the family in a form that they can understand.	*1. News should be shared in a face-to-face discussion in privacy* *2. Written information should be provided to support verbal communication* *3. Emotional support should be available to families when significant news is being shared* *4. Information conveyed should be available to families when significant news is being shared* *5. Parents should be treated with openness and honesty* *6. If possible, families should be together to receive the news*
Standard 2 Every child and family diagnosed in the hospital setting should have an agreed transfer plan involving hospital, community services and the family, and should be provided with the resources they require before leaving hospital.	*1. Community services should be notified as soon as it is practical to do so. This may include children's hospice services* *2. There should be community in-reach to the family in hospital and outreach to primary care services* *3. Planning should begin as soon as possible and a clear plan for transfer should be agreed with the child, family, hospital and community services* *4. A lead community children's nurse should be agreed before transfer and the child's GP should be included. Clear plans should be in place for shared medical care 5. Equipment and supplies should be provided before transfer* *6. Transport should be arranged* *7. Training should be provided for parents and carers prior to transfer* *8. Clear lines of communication should be agreed* *9. A home visit should be arranged within three days of transfer* *10. A 24-hour contact number should be provided to the family* *11. If transfer to a children's hospice is planned, a member of the team should meet the family at the hospital before discharge where possible*

Standard 3 Every family should receive a child and family centred multi-disciplinary and multi-agency assessment of their needs as soon as possible after diagnosis or recognition and should have their needs reviewed at appropriate intervals.	*1. Those undertaking assessments should be skilled in the assessment of children with palliative care needs* *2. Children and families should have their strengths, needs and wishes assessed as soon as possible after diagnosis or recognition in partnership with the family* *3. A holistic, multi-disciplinary and multi-agency approach should be used to avoid the need for multiple assessments* *4. The child or young person should be the central focus of the assessment* *5. Care should be taken to include the strengths and needs of fathers, siblings and the wider family* *6. To enable shared assessment, consent needs to be gained and confidentiality assured* *7. Assessment information should be part of a family held document*
Standard 4 Every child and family should have a multidisciplinary, multi-agency care plan, developed in partnership with them for the delivery of co-ordinated care to enhance family strengths and meet need. A multi-disciplinary and multi-agency team should be identified in agreement with the family and use key working principles. Wherever possible this should involve all agencies involved in supporting the child and family, including the child's community nursing team, allied health professionals, hospice, local acute and tertiary hospital services, education, social care and short break services.	*1. Every family should have a team that uses key working principles to co-ordinate the plan* *2. Relevant and timely information should be available for the child and family* *3. The plan should take account of the whole family's needs and wishes* *4. The plan should be comprehensive*

Standard 5 Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this.	*1. Professionals should be open and honest with families when the approach to end of life is recognised* *2. Joint planning with families and relevant professionals should take place as soon as possible* *3. A written plan of care should be agreed and shared with emergency services, including decision about methods of resuscitation* *4. Care plans should be reviewed and altered to take account of changes* *5. There should be 24-hour access to pain and symptom control including access to medication* *6. Those managing the control of symptoms should be suitably qualified and experienced* *7. Emotional and spiritual support should be available to the child and family* *8. Children and families should be supported in their choices and goals for quality of life to the end* *9. There needs to be clear understanding of the formal processes that are needed after death and the timing of these*
Standard 6 Bereavement support should be provided along the care pathway and continue throughout the child's death and beyond.	*1. The family should be allowed time and privacy with their child* *2. Parents should feel in control of events before and after the death and be able to follow their own choices and wishes* *3. Families should all be offered bereavement support, and this offer should be repeated as it may not be heard or taken up in the first instance* *4. The bereavement needs of siblings should be recognised and supported*

Appendix 3 PPCW Community Respite Guide

Paediatric Palliative Care Worker

Respite in the community risk assessment guide

When arranging respite for a child with the parents, make sure that you have chosen the place you will be going. This is to prepare what you need before you go, and to make sure the parents and child are happy for you to go there.

You will need to risk assess each outing according to the needs of the child you are taking, each child's needs will differ, meaning each trip out will need to be uniquely risk assessed.

What to look for when risk assessing places in the community.

- Disabled toilet access and changing areas for young children/ babies
- Disabled access to any buildings
- Close parking (if needed)
- On a bus route (if needed)
- Availability. Do you need to pre book sessions?
- Safe accessible play areas
- Safe places to feed, some children will need adequate seating when feeding, others may be fed in their wheelchairs/buggies. Always check any feeding plans and follow SALT guidelines if the child has them.
- Shaded areas to play and rest if needed
- You have adequate seat belts or correct car seats in your own vehicle before taking the child out
- If you are using the bus, check with the family that it is safe for the child to do so.

What do you need before going on your respite outing?

- Any and all emergency care the child may need, spare milk, water, sun cream, epi pens.
- Contact numbers for parents or carers
- A fully charged phone
- Tell a colleague where you will be
- Make sure you have read and have access to the child's care plan. Either in hard copy or through EMIS
- Consent from the parents or carers
- Snacks and water provided by the family for the child (if needed)

Appendix 4 PPCW Family Home Respite Guide

Paediatric Palliative Care Worker

Respite in the family home risk assessment guide

When respite with a child is in the family home it is still important to do a risk assessment, each home will require a risk assessment as each child will have different needs.

What to look for when risk assessing in the family home.

- Are there stairs that could be a hazard to you or the child?
- Does the home have safe outside access
- Are there any pets in the home
- familiarise yourself with the home
- Do you know where the child's emergency equipment is?
- Do you have correct contact numbers
- consent forms

How to prepare for respite in the family home

- Read the lone worker policy
- Make sure your colleagues know where you will be and for how long
- Make sure you have a fully charged phone
- Have access to the child's care plan either in hard copy or on EMIS