Family Nursing & Home Care

Jersey Hospice Care

your care, your choice, your time

Standard Operating Procedure (SOP)

Palliative care provision at end of life GSF red/amber

September 2021

Jersey Hospice Care

Family Nursing & Home Care

Document profile

Type	Standard Operating Procedures
Name	Standard Operating Procedures – Palliative Care provision at end of life GSF red/amber
Category	Clinical
Version	1
Author	Working Party Leads – Tia Hall (Operational Lead for Adult Nursing Services) Michelle Nelson (Deputy Director of Palliative Care Services, JHC) Kim Hancock (Senior Nurse, JHC) Odette Popeea (CNS, JHC)
Approved by	Organisational Governance Approval Group
Date Approved	6 October 2021
Review Date	1 year from aproval
Person responsible for review	Operational Lead for Adult Nursing Services Clinical Effectiveness Facilitator

Policy Amendments

Version Number	Amendments
V2	Updated to reflect red/amber GSF, updated definition specialist palliative care, updated funding information , links to JCC homecare standards , MDT meeting

Jersey Hospice Care

Family Nursing & Home Care

Table of Contents

Introduction

This standard operating procedure (SOP) has been developed to guide the practice of Family nursing and homecare (FNHC) staff in partnership with Jersey Hospice Care (JHC). It also provides a framework for the provision of safe and effective end of life care for patients in their preferred place of care and death.

Principles

The following are overarching, guiding principles for safe and effective practice when using this SOP.

- The SOP does not replace clinical judgement which should be always used.
- There are additional SOP's and policies that inform palliative care.
- A clear rationale should be presented/recorded in support of all decision making.
- Practice should be based on the best available evidence/
- Appropriate escalation when care needs require this.
- Where care is shared, FNHC and JHC will work to agreed joint policies and care pathways including anticipatory medication, rapid discharge guidelines, recognising when someone is in the last days of life using Gold Standards Framework (GSF) and personalised care record (PCR).
- FNHC will work alongside JHC when specialist care or additional support is required by the patient and their family.
- FNHC and JHC have agreed this SOP and will work within the Jersey Care commission standards and the principles of the GSF to enable all people nearing the end of their life to receive the best possible care to meet their needs and accommodate their wishes.
- FNHC are commissioned to deliver generalist palliative care to patients in the place they call home from 18 years of age irrespective of diagnosis.
- The Specialist Palliative Care Team (SPCT) is a commissioned service and has a Service Level Agreement (SLA) with Health and Community Services (HCS). The SLA defines the specifics of the service with agreed outcome measures linked to 'Ambitions for Palliative and End of Life Care: a national framework for local action 2015-2020'.
- The SPCT and FNHC home nursing service are regulated services and inspected annually by the Jersey Care Commission (JCC). The Jersey Care Commission operates under the Regulation of Care (Jersey) Law, 2014, and specifies healthcare providers must adhere to Regulation of Care (Standards and Requirements) (Jersey) Regulations 2018.
- Where potential safeguarding issues are identified, FNHC and JHC will follow the guidance and processes of the Jersey Safeguarding Partnership Board.

WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families who are facing problems associated with life –threatening illness. It prevents and relives suffering through the early identification, correct assessment and treatment of pain and other problems.

Palliative care is the prevention and the relief of suffering of any kind- physical, psychological, social, or spiritual- experienced by patients living with life limiting illness. It promotes dignity, quality of life and adjustment to progressive illness, using best available evidence.

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 multi-disciplinary 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

http://www.who.int/cancer/palliative/definition/en/ [Accessed on 20th February 2016]

What is specialist palliative care and the role of the SPCT?

Specialist palliative care is provided by experts in providing palliative care and will have training and experience in this area. They will be involved in managing more complex care problems. Specialists usually work in teams to provide more joined-up care. Complex care problems may include complex symptom management, physical, psychological, social, ethical or spiritual dilemmas regarding treatments and other decisions. (NHS, 2016)

Where reference is made to 'complexity,' this encompasses patients who may have multiple co-morbidities, intractable symptoms and multi-dimensional aspects of need including psychosocial factors and communication issues (Schaink et el, 2012).

Complexity may not only refer to the patients' level of need, but it may also refer to the perceived complexity of the patient need and the knowledge and skills of the non-specialist practitioner. (Commissioning Guidance for Specialist Palliative Care, 2012)

Patients with a life limiting illness and perceived complex needs differentiates those who require input from Specialist Palliative Care services and those whose needs can be met by professionals who are generalists in palliative care. (Carduff et al, 2018).

Patients will need to be assessed and reviewed throughout the course of their illness. Reassessment will be determined by phase of illness; stable, unstable, deteriorating and dying (Kings College London, 2015) at the following stages:

- Time of diagnosis
- As treatment is commenced
- Completion of treatment
- Disease recurrence or relapse
- As palliation is introduced
- End of life care/bereavement
- At any other time as requested by patient, carer or health professional.

Specialist Palliative Care is provided by a multi professional team who have undergone specialist and enhanced training at degree, post graduate and master's level.

Please note other standard operating procedures are available including those that are part of policy and guideline documents.

Jersey Hospice Care

Family Nursing & Home Care

Identifying People Nearing the End of Life and Planning their Care

Purpose

To provide a framework for assessing patients nearing the end of their life (EOL) in order to plan appropriate care needs.

Scope

This SOP pertains to patients in receipt of Adult Nursing Services thought to be nearing the end of their life. It encompasses assessing patients' stage of care need, assessment including anticipation of care needs, a multidisciplinary approach to meeting these needs, and care planning and review.

Core Requirements

- FNHC will work in partnership with JHC, GP's and any other healthcare providers to identify patients in the last year of their life and identify their stage according to the GSF.
- Stages should be identified as follows:
    - A Blue –diagnosis stable/ year plus prognosis.
    - B Green –unstable/advanced disease/Months prognosis.
    - C Amber-continuing care/deteriorating/weeks prognosis
    - D Red- Final days /Terminal care /days prognosis
    - Navy –after care.
- Consent, respect and patient choice/preference should be at the centre of planning patient care. Palliative care is based on multidisciplinary assessment of a patient's needs in line with the GSF.
- FNHC & JHC will actively participate in island wide Multi-Disciplinary Team (MDT) meetings.
- GP practices will lead their GSF meeting informed by their GSF register.
- FNHC and SPCT will attend GSF meetings with their own active case load to discuss patients coded Amber/Red.
- Joint assessments with other healthcare professionals should be undertaken for complex/ EOL patients.
- Where patients are discharged home from Hospice In Patient Unit (IPU) a discharge planning MDT should be organised prior to discharge with key healthcare professionals taking over care in community, patient, and family if appropriate, to facilitate a safe and coordinated transfer.
- FNHC will work closely with the SPCT, GPs and other healthcare professionals to assess current and future clinical and individualised care needs. FNHC and SPCT will have monthly meetings to agree care coordinator and discuss patients with general palliative care needs and specialist palliative care needs.

- Care will be reflected in an Individualised care plan which will incorporate anticipation of care needs and review.

Individualised care plans will identify goals, aims and outcomes.

- Detail how the person receiving care wishes to achieve the goals and aims.
- Detail what care/support workers will do to help people achieve the goals and aims.
- Be based upon current best practice guidance and evidence.
- Include personal preferences.
- Ensure that consent is gained to carry out any care or support.
- Include information about any specialist equipment that is needed.
- Show who will be involved in developing and reviewing the plans.
- Demonstrate that people understand and know how to change any decisions about their care or support.
- Detail how success and outcomes will be reviewed.
- Show when the care/support plan needs to be reviewed. .
- During the last days of a person's life the personalised care record (PCR) will be used to support effective care planning and joint working across JHC, FNHC, GP and care provider.

Funding Streams for Palliative Care

Purpose

To provide patients with options in a timely manner, for accessing funding for palliative / end of life care.

Scope

Patients receiving palliative/end of life care from Adult Nursing Services requiring financial support including finance to expedite discharge from hospital or funding to stay at home to die.

Core Requirements

- FNHC and JHC can signpost patients and their families to apply to Social Security for long term care funding / Income Support as their care needs increase as part of GSF. FNHC / JHC should liaise with palliative care social worker. This can be accessed here.
- FNHC may have access to limited charitable donation that can fund equipment and additional homecare for patients who do not have access to funds at the end of their life in order to prevent their admission to hospital if they wish to die in their own home. Any requests to access this charitable fund to provide care or equipment must be agreed by adult service operational Lead or deputy before an offer is made to the patient or their family.
- FNHC & JHC are able to signpost to other charitable organisations that may be able to support with funding.

Jersey Hospice Care

Family Nursing & Home Care

Co-ordination of Care

Purpose

To provide clarity regarding the coordination of a patient's care and the availability of Family Nursing & Home Care (FNHC) and Jersey Hospice Care (JHC) services.

Scope

This SOP covers care coordination and outlines FNHC and JHC service provision.

Core Requirements

- Care is coordinated based on the individual's needs. A patient with generalist palliative care needs care would be coordinated by FNHC and a patient with specialist palliative care needs care would be coordinated by the SPCT.
- **Generalist -** Generalist palliative care is treatment, care, and support for people with a life-limiting illness, and their family and friends. It is sometimes called 'supportive care'. General health and social care professionals give day-to-day palliative care to people as part of their roles.
- **Specialist -** Specialist palliative care is provided by experts in providing palliative care and will have training and experience in this area. They will be involved in managing more complex care problems. Specialists usually work in teams to provide more joined-up care. Complex care problems may include complex symptom management, physical, psychological, social, ethical or spiritual dilemmas regarding treatments and other decisions. (NHS, 2016)
- JHC, FNHC and GP practices can access each other's EMIS records after first seeking the consent of the patient or where that is not possible where it is in the patient's best interest to ensure coordinated care.
- The care coordinator will be established at one of the following meetings and reviewed according to the persons condition which may fluctuate, stabilise or deteriorate:
  - Palliative MDT meeting
  - GSF meeting
  - Joint FNHC/JHC monthly meetings (East/Town West /West /Town east)
- The named care coordinator must be clearly recorded in the patient's EMIS record.
- The care coordinator will take responsibility for contacting all organisations involved with the patients care to ensure that they are aware of the name and contact details of the coordinator. The care coordinator will also take

responsibility for informing the patient and their family with who to contact and all contact details.

- FNHC are the main providers of generalist palliative care in a patient's home.
- FNHC and JHC work in partnership to ensure that referrals for generalist care are signposted to FNHC. This needs to be discussed at the point of referral with the referring Health Care Professional.
- Each organisation must respect and adhere to the decision made as to who the main care coordinator is. This will ensure the patient and their carers know who the first point of contact is thereby avoiding confusion and delay in an appropriate and timely response.
- FNHC are able to provide care 7 days per week from 08.30 hrs - 23.00 hrs depending on patients' care needs.
- The SPCT are available Monday – Friday 9am-5pm, requiring a minimum of 2 CNSs on duty at any one time. Weekend and Bank Holidays 9am-5pm, with 1 CNS on duty.
- JHC accepts referrals for patients with a progressive life-limiting illness.
- Referrals are based on need, not diagnosis. The service is available to all organisations across the island.
- Referrals to the SPCT can be made by any healthcare professional if the lead medical physician in charge of the patient's care agrees with the referral.
- All referrals must be in writing and posted or faxed to JHC, or they can be emailed using the secure egress system to the Community team email address. The preferred mode of referral is by completion of JHC's Referral Form which can be found on JHC website although letters from professional colleagues are also accepted. However, if inadequate clinical information is provided, this may result in a delayed response while further detail and clarity of information is sought.
- If the referral is urgent (within 24 hours response time) the written referral should be supported with a telephone call to the SPCT explaining why the referral is deemed urgent. All referrals should specify the response time required and document clearly the reason for referral. Patients and families can request a referral, but this must be completed by the treating team or lead physician.
- Triage of all new referrals is undertaken by a member of the hospice medical team. See Specialist palliative care referral pathway (appendix 2).

Jersey Hospice Care

Family Nursing & Home Care

Weekly Palliative Multi-Disciplinary Team (MDT) Meeting

Purpose

- A team approach to care is one of the key elements of effective palliative care service delivery.
- Multidisciplinary care involves appropriately utilising knowledge, skills and best practice from multiple disciplines to reach solutions based on a new understanding of a complex situation.
- An MDT makes recommendations rather than decisions.
- Recommendations can only be as good as the information available to the MDT with the appropriate disciplines present.
- A MDT discussion should take into account the patient's views, preferences and circumstances wherever possible.
- Recommendations/outcomes should be revisited to ensure they have been effectively addressed.

Scope

For core disciplines to facilitate collaborative care planning for all people with a life limiting illness, providing a forum for multiple providers to share their expertise and ensure effective, individualised evidence-based palliative care decision making.

Core Requirements

- MDT meetings are held on a weekly basis at Jersey Hospice Care.
- The core membership consists of:
    a) Consultant in Palliative Medicine (Chair)
    b) Either/or Associate Specialist/Staff Grade palliative doctor (deputise in Consultant's absence)
    c) Clinical Nurse Specialists- SPCT
    d) Family Nursing & Home Care representative
    e) In Patient Unit – nurse representative
    f) Palliative Care Pharmacist
    g) Social Worker
    h) Spiritual support
    i) Emotional/Bereavement service
    j) Palliative rehabilitation team/day hospice via King Centre
    k) General Practitioners may be invited to attend
    l) other members of the team including SALT, Respiratory CNS , Cardiac CNS etc

- All health care professionals involved in the core group are expected to attend on a weekly basis.
- Those patients discussed at MDT and with capacity to do so, must have given explicit consent prior to the meeting. If a patient lacks capacity then a 'Best Interests' decision can be made in accordance with Capacity and Self Determination (Jersey) Law 2016.
- Any core member can present a patient to the MDT meeting.
- The category of patient for MDT discussion are either 'new referrals' or 'patients with complex needs'
- In identifying patients with complex needs, use of evidence based clinical indicators e.g., Gold Standards Framework: Prognostic Indicator, Palliative Care (OACC) Phase of Illness, the Australian Karnofsky Performance Status and involvement of multiple providers in the patient's care can be considered. It is recommended that these tools be updated at the MDT meeting following discussion.
- New patients- the presenting clinician must have prepared ahead of the meeting to enable a succinct presentation of the patient.
- Patients with complex needs- Complete the MDT EMIS template prior to the MDT meeting and make the MDT coordinator aware of this 24hours prior to the MDT. There is flexibility for cases that may need to be added at the last minute due to clinical urgency and the MDT Chairperson should be made aware of these cases prior to the commencement of the meeting on the day.
- For FNHC patient's not known to JHC and therefore not traced onto JHC EMIS, the presenting District nurse can logon to FNHC EMIS at the start of the meeting to highlight the patient of concern.
- The person referring a patient to the MDT must make every effort to attend the scheduled meeting to present the case, contribute to the discussion which will enable them to give feedback on the outcome, as appropriate, to the patient. If the referrer is unable to attend, a thorough handover should be given to another appropriate attendee who can present and report back the outcome of the MDT to the referrer.
- A record of the MDT discussion must be made on the patient's EMIS health record, to include details of what was discussed, the proposed action plan, and the name of those persons who will carry out the action.

N.B: - Staff should refer to the MDT Operational Policy for more detailed guidance regarding the MDT process. For FNHC staff this document can be found in 'central filing'. For JHC staff this document can be found on the JHC intranet under 'policies and procedures.

Jersey Hospice Care

Family Nursing & Home Care

Joint Working with Registered Homecare Provider (Jersey Care Commission) at End of Life (GSF Code Amber / Red)

Purpose

FNHC and JHC recognise the important role of registered homecare providers and are committed to working in partnership to ensure that the patient and their family receive holistic care.

Scope

This SOP outlines joint holistic care by nursing and registered homecare providers in the GSF needs based coding Amber/Red of EOL care.

Core Requirements

- When a patient is thought to be entering the last weeks to days of life, and are GSF Needs Based Coded Amber or Red, and they only have generalist palliative care needs, their care will be coordinated by the FNHC DN team unless otherwise stated. . The details of the care coordinator will be communicated to the registered homecare provider, the patient and their family and the patients GP.
- When FNHC DN team are coordinating care, they will take responsibility for liaising with JHC for specialist advice/ support rather than the registered homecare providers contacting JHC SPCT directly.
- When the registered homecare provider requires urgent advice or support from FNHC between the hours of 08.30- 16.30 hrs they should contact the team on443603 or via switchboard at JGH after 16.30 hrs and before 23.00 hrs and between 08.30 hrs and 23.00 hrs weekends.
- The registered homecare provider should advise the clinical admin/Nurse of the nature of the urgent concern that they have. This will be communicated to the clinical triage Nurse in FNHC who will endeavour to respond to requests for urgent advice and support within 1 hour. Urgent requests would include management of distressing symptoms not resolved by measures documented in the care plan.
- FNHC and JHC are not able to offer an emergency service, and should the patient suffer from unanticipated symptoms, severe distress or pain then care providers should contact the patients GP or ambulance in an emergency without delay ensuring that the patient's wishes are made known to the ambulance crew on arrival. Ensure patients have a treatment escalation plan in place should this occur.

- Appropriate response to a sudden change in condition should be documented in the care plan developed by FNHC to ensure that the response meets the patient's wishes.
- FNHC DN team will work with care providers to develop care plans that take into consideration the patients changing nursing /care needs. This will include turning/moving care plans, management of pain or other symptom management, ceilings of care .This list is not exhaustive and will reflect the patients changing care needs.
- Where a registered homecare provider is asked to support medication administration they should be advised who to contact to seek advice from. This will generally be the DN service during their core working hours 8.30-23.00hrs 7 days a week. Outside these hours, i.e., between 23.00hrs-08.30hrs the out of hours GP service JDOC should be contacted. Provision for out of hours support must be documented clearly in the patients care plan. Copies of care plans should be placed in the patient's supplementary record in the home.
- When a person is in the last 48hrs of life they will have a hard copy of the personalised care record (PCR) which is a record for all professionals /care providers to complete. Once the patient has died the PCR will be scanned and uploaded to EMIS by either JHC or FNHC, then the hard copy kept by the team coordinating the patients care.

Care After Death

Purpose

To provide dignified care after death, to the patient, family and significant others.

Scope

This SOP encompasses care after the death of an adult.

Core Requirements

- FNHC will continue to provide care after death for patients (Last Offices) and emotional care to support families and significant others.
- FNHC and JHC will agree who will retrieve medical devices and organise with the family to contact equipment supplier to collect equipment.
- FNHC and JHC are responsible for ensuring that relatives/friends know who to call when their loved one dies as part of priorities of care.
- When there has been joint involvement with the patients care, both organisations will liaise to ensure that care after death is coordinated and not duplicated.
- Whilst each organisation is responsible for the collection/removal of their own equipment, wherever possible, a coordinated approach should be made where both organisations have equipment that needs to be collected. This will minimise disruption to the family at a difficult time.
- It is the responsibility of both FNHC and JHC staff to ensure either the original or a copy of the patient's paper records are retained, in particular medication administration charts, to ensure a complete and evidenced record of events is stored as per each organisation's record keeping and retention policy and procedure.
- JHC offer a bereavement service if required, however it should be acknowledged that individuals and families can be remarkably resilient after the death of their loved one and will seek support and care from a range of professional services and most importantly each other.