

NHS DORSET, BOURNEMOUTH AND POOLE

OPERATIONAL PROTOCOL TO SUPPORT WORKING ARRANGEMENTS UNDER THE HOSPICE CONTRACTS WITH NAOMI HOUSE AND JULIA'S HOUSE AND PAN DORSET CHILDRENS SERVICES

1. INTRODUCTION

- 1.1 This operational protocol has been developed in collaboration with the two Dorset primary care trusts, NHS Dorset and NHS Bournemouth and Poole, together with the pan Dorset children's community nursing services Dorchester County Hospital Foundation Trust and Poole Hospital NHS Foundation Trust and the two hospices serving the Dorset locality Julia's House and Naomi House and forms the agreements reached for local processes alongside the Hospice specification and the alignment with local continuing health care processes.

2. DEFINITIONS

- 1.1 This protocol makes reference to the following terms;
- **Continuing Healthcare** This will be required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal / mainstream or specialist services. This usually consists of a package of care comprising of regular and planned complex medical or nursing interventions. Continuing care does not cover children and young people with care needs that may be appropriately met through existing universal or specialist health services.
 - **Short breaks** These are in some cases less frequent but are generally joint funded and are on a planned and regular basis and form part of an integrated programme of support which is regularly reviewed.
 - **End of Life** The end stage of life in children is particularly difficult to determine in children due to the rarity of many of the medical conditions and the less predictive nature of terminal illness in this age group. The definition of its beginning is variable according to the individual child and young person and professional perspectives. For the purposes of this protocol, end of life describes services to support children with advanced progressive incurable illness who are in an immediately life threatening palliative stage of their illness and condition where the service is supporting the child to live as well as possible until they die. In all cases the focus is on the quality of a child's life and on support of the whole family.
 - **Potential end of life care** Where clinicians would not be surprised if the child or young person dies within the next six months

3. LOCAL ASSESSMENT PROCESSES AND REFERRAL ROUTES

- 3.1 In Dorset the children's complex care services work to national guidance implemented locally in accordance with the National Framework for Children and Young People's Continuing care 2010.

4. REFERRALS

- 4.1 The referral of a child with possible eligibility for Continuing Care for children and Young people can be made by any of the following clinicians or practitioners

- Childrens Community Nurse
- Paediatrician
- Social worker
- LD Nurse
- Mental Health Nurse (CAMHS)
- School Nurse
- Childrens Nurse
- Therapy worker
- Paediatric consultant

This list is not exhaustive

END OF LIFE REFERRALS

End of life referrals should be initiated using the fast track route. **Fast track** applications will be progressed through the primary care trust lead in collaboration with lead professional / clinician who is initiating the application. The primary care trust will progress the need for hospice care where appropriate. Referrals from service providers will be progressed by the primary care trust only when there are clear identifiable needs and there is no lead professional identified.

5. INITIATING APPLICATIONS

- 5.1 Applications can be initiated by any clinician with the NHS who has undergone the new framework training session. An NHS employed clinician can be a nominated health assessor such as a paediatrician, a children's nurse or therapy worker and includes tertiary centre clinicians. Ideally it will be the clinician practitioner that has been involved in the care, or who knows the child and young person. This approach is in contrast to the previous primary care led process and aligns with the new framework which reflects a team around the child approach to initiating and progressing applications.

6. LOCAL CARE PATHWAY FOR CONTINUING CARE

- 6.1 There are only a small number of local variations and these are set down in the specification in section 4.5 Also found at 4.5 is the Aligned budget (Joint funding) care pathway which is operated in NHS Dorset.

7. LOCAL CARE PATHWAY FOR JOINT FUNDED CASES (NHS DORSET AND DORSET CHILDREN'S SERVICES- ALIGNED BUDGETS)

- 7.1 NHS Dorset AND Childrens Social Care Dorset County Council have an aligned budget arrangement across the two agencies. The arrangement was initiated to meet the needs of a small cohort of children who are in a palliative phase but not immediately end of life phase acknowledging for this group of children there will be times when they require support services of a lesser intensity and may require more intense complex interventions and support at some point and these children and young people may in the future require a continuing care package.
- 7.2 The budget arrangement meets the needs of children who may be in this group and they do not have clear defined health or social care need or predominance for health care services or social care services, but the two respective partners acknowledge that there are joint responsibilities to be met in the best interest of the child young person and their family.

8. ASSESSMENT

- 8.1 Children who meet the Children's Community Nursing team criteria will be referred to the service. These children will be most likely to have a consultant paediatrician in either a secondary or tertiary care centre or managing their care or condition. Every child accepted for referral will have their care supervised and overseen by a children's community nurse. Some direct care will be provided by a health care support worker but accountability will still lie with the designated children's community nurse or lead professional where appropriate and;.
- 8.2 Children will be accepted for assessment if it is judged that;
- The child or young person will require a package of care because their needs cannot be met by mainstream and universal services i.e. continuing health care
 - An early discharge can be facilitated
 - Admission to hospital can be prevented
 - Care is required to support end of life care- i.e. the child has a progressive health condition that is likely to result in a shortened life expectancy
 - Family or other crisis
- And in relation to short breaks if;
- The child or young person's need for planned home or residential short breaks cannot be met by other services at that time and without nursing intervention a health crisis may ensue, and the hospice can assist;
- 8.3 Assessments for care packages will be undertaken within the timeframes of the national care pathway and decisions to fund will be made alongside this framework except where the commissioners make a decision outside of the decision making timeframes due to the urgency of need; in this situation this will be taken for ratification at a later date so as not to delay the implementation of the care package.
- 8.4 In some cases decisions may impact upon other agencies or multi agency care will be proposed. Therefore in such cases a holistic health and social

care assessment will take place jointly with the children's social care team and community children's nursing team. There will be some cases depending upon need that the assessment will be single agency and possibly, depending upon the circumstances this may require a fast track route to continuing care funding and service delivery and the hospices ability to provide will be considered. It is acknowledged that in some cases it will be difficult for the hospices to provide for 24/7 care provision at short notice and this will need to be considered on a case by case basis, bearing in mind the current hospice capacity to provide alongside existing short breaks provision and current in reach and outreach arrangements by individual hospice.

- 8.5 A clear review period will be specified within the assessment.
- 8.6 Each child or young persons and their family's needs for hospice care will be assessed on an individual basis.
- 8.7 Referrals will not be accepted beyond the young person's 18th birthday unless the child is already known to the service. For the purposes of this protocol, this will be applicable to Naomi House where the service can be extended into adulthood up to age 32 years. In other cases where the young person is over 18 years the referrer will be directed to adult continuing care services locally. Where the young person is known to the children's continuing healthcare services then the referral will be progressed through local transitions processes.
- 8.8 Assessments and applications for children's and young peoples continuing care will align with national processes locally and include;
 - All of the child and young persons needs together in a holistic approach
 - These assessments will be primarily led by the children's community nursing services teams Dorchester and Poole however contributions to the multi agency planning meetings will include involvement and contribution from other provider agencies where applicable and these reports will be provided using the pan Dorset single integrated assessment tool.
 - Proposals to meet immediate need – with estimated costs from an approved/ preferred provider list or acute trust provider where applicable
 - Recommendations for longer term support
- 8.9 It is acknowledged that the hospices may not be able to provide such care at short notice where planning and anticipation has not been possible. It may be that the care delivery in such circumstance may be provided on a multi provider basis.
- 8.10 A clear review period will be specified in the assessment and an integrated care package may be provided where appropriate.

9. DECISION MAKING

- 9.1 **The process for decision making in NHS Dorset** Decisions regarding eligibility to continuing care and funding are made in accordance with national policy and local processes as per care pathways as per section 4.5 of the specification. There is only one local variation and this is applicable to NHS Dorset and is asterisked on the care pathway. NHS Dorset and Children Who are Disabled East and West teams Dorset County Council have an aligned budget arrangement in place and applications can be raised as per the care pathway in section 4.5

Decisions regarding eligibility can be made outside of the panel process such as in situations of crisis or urgent need as per care pathway section 4.5

- 9.2 Where time permits and cases are taken to panel, the panel will consider each individual application. The application will be considered by a multi-agency decision making panel which meets each month. Alongside this process, in Dorset, the children's resource panel will consider cases for the aligned budget processes. This gives an opportunity at the start and middle of each month to consider applications and allocation of resources.
- 9.3 Decisions to fund will be made alongside this framework except where the commissioners make a decision outside of the decision making timeframes due to the urgency of need, this will be taken for ratification at a later date so as not to delay the implementation of the care package.
- 9.4 Whilst principles in decision making will be made and based upon inclusion and choice, step down care will be explicit and planned depending on the ongoing needs of the child.
- 9.5 Each locality primary care trust locality will have much the same quorum for each of its decision making panels, according to their terms of reference.
- 9.6 Professionals who have submitted applications will not have a decision making role in either panel process, although it may be that the health or social care professionals may be invited to be present for clarification of information if required. The panel will make decisions based upon the following principles:
- Clinical need;
 - Clinical and social need where there is no predominance for either health or social care but clear health responsibilities;
 - Best value;
 - Equity in terms of anticipated health outcomes and resources available compared to other children and young people and their families with identified needs.
- 9.7 Urgent referrals that require intervention to prevent or address crisis situations will be prioritised, as stated previously; decisions will be made outside of the routine panel processes to ensure that a swift response is achieved. In these situations the panel will review these decisions

retrospectively and if necessary draw up subsequent guidelines to continually inform the processes in place.

- 9.8 **The process for decision making for NHS Bournemouth and Poole;** The multi disciplinary team MDT recommendation of eligibility and proposed care options including the written evidence supporting the recommendation is sent to the PCT who will check the evidence against the recommendation and make a decision as to the eligibility and appropriate care package
- 9.9 If a case is borderline or ambiguous or the MDT feels unable to make a recommendation or there is disagreement about the recommendation, the case will be taken to a Multi-Agency Panel for a decision.
- 9.10 Professionals involved in the MDT will make recommendations but the final decision will be made by the PCT. If the evidence to support the recommendation is available it is unlikely that the MDT recommendation will be overturned by the PCT. Appeal and Dispute Procedures will be followed in the event of disagreements.
- 9.11 The funding for all professionally agreed packages of care provided by health has to be agreed by the NHS Bournemouth and Poole Joint Commissioning and Planning Directorate prior to commencement, except in the case of Fast Track/End of Life when a care package may be provided urgently until an agreement has been reached.
- 9.12 **Generic to both primary care trusts** In exceptional circumstances where the primary care trust commissioners cannot be contacted such as out of normal working hours or bank holidays the children's community nurse or matron may at their clinical discretion arrange appropriate care provision of care. A discussion with the primary care trust commissioners need to be informed and a discussion take place no later than 72 hours after and a panel meeting or equivalent process in neighbouring primary care trust be arranged to review the decision.
- 9.13 It must be noted that the commissioning manager has ultimate responsibility for the commissioning judgement and reserves the right under exceptional circumstances to individually make a decision outside panel processes.

10. COMMUNICATION

- 10.1 The primary care trust commissioner will communicate to the child or young persons family, and involved professionals and agencies including the children's community nursing team advising them of the outcome of the application within five working days of receipt of and decision making in NHS Bournemouth and Poole, and in NHS Dorset, five days of the panel meeting and the decision making. This may be a preceded by a face on face discussion where appropriate on behalf of the panel chair.
- 10.2 If the referral and application is accepted the clinical responsibility will remain with the clinical professional or team headed by the child or young person's consultant and child or young person's general practitioner and the other agencies working in partnership with them. The children's community nursing team will continue to have the responsibility for the

continuation and organisation of the community nursing care interventions.

11. APPEALS

- 11.1 Families may appeal in writing to the primary care trust in accordance with local processes. Each primary care trust will have its own processes.
- 11.2 In NHS Dorset a second scrutiny panel will then meet to assess the original decision. This panel will be a neighbouring primary care trust and will be representative of health, social care and education services.

12. CARE DELIVERY

- 12.1 The hospices have set down clearly the package of care they intend to provide to the identified children in collaboration with the primary care trusts within the Dorset locality. Julia's House will provide to the named children a 200 hour per annum package consisting of in reach and outreach sessions. Naomi House will provide to the named children up to 16 nights per year.
- 12.2 It is acknowledged that both hospice providers may choose to offer components in addition to these standard arrangements within their charitable funding to these named children and others that have not been identified. The two hospices have confirmed that they reserve the right to provide services to children young people and their families who meet their hospice referral criteria but may not meet the threshold for services from the NHS. Both hospices confirm that they have their own "back up" crisis packages for families who have exhausted the standard arrangements but present with additional identified needs from time to time that the hospice may choose to fulfil or not.

CARE DELIVERY FOR NEW USERS

- 12.3 Care package arrangements will be commissioned on the basis of a multi agency assessment of need This may or may not equate to the each hospices current standard offer.
- 12.4 The hospices have set down the range of services that each one can provide under the specification. At this point each commissioning primary care trust party to the contract will need to approach the hospices on a case by case basis to determine whether the individual hospice can provide or not. These referrals and resulting associated activity will be monitored and reviewed at intervals to inform strategic commissioning needs and developments for the future.

13. QUALITY MONITORING - STANDARD PACKAGE OF CARE MONITORING FOR EXISTING USERS

- 13.1 Existing users have been made a standard offer for 2011. It is acknowledged that this has not been established on the basis of need by the NHS. At this time parents book their care and support needs directly with the hospice provider. This means that families may not be able to

have precisely the times and dates that they wish although both hospices confirm that they will try to accommodate the wishes and requests of families where possible.

- 13.2 For the purposes of confidentiality it is proposed that each individual hospice will provide a copy of the letter setting down how they intend to provide for the children in terms of the agreed package and how unfulfilled hours will be provided for and how choice around bookings will be offered. These will be included within the specification.
- 13.3 The primary care trusts have clearly advised the two hospices that the delivery of the standard packages of care will be monitored. This is to ensure that hours and sessions are not accumulating and that the commitment to the agreed packages can be delivered within reasonable timeframes and in accordance with family needs. New packages will also be subject to ongoing monitoring.
- 13.4 Therefore arrangements will be put in place to monitor collaboratively the delivery time frames. These arrangements will take the form of meetings between provider and commissioner on an agreed regular basis. It is likely that these meetings will follow models previously used with other providers. The primary care trusts will need to set up a bi monthly meeting respectively with the two hospices to determine the consistent activity alongside the agreed standard package. This will serve as an early warning to commissioners if elements of the package cannot be delivered within a specific timeframe agreed as four weeks.

14. DATA REPORTING RETURNS

- 14.1 Each hospice under the new contractual arrangements is required to provide a range of reporting data around service delivery information. This needs to be provided in electronic format to the respective commissioners as set down clearly in the specification. Section 7.2 Page 12. The data must include all detailed data/ reporting requirements and be presented in either Word or Excel programme format within 6 working days of each quarter monitoring period to the respective commissioner. Monthly data reporting needs to the commissioners within 6 working days of the end of the month.
- 14.2 Each partner will monitor net gains or losses of support to individual families and identify resource gaps for analysis.

15. REVIEWS OF EXISTING CHILD AND YOUNG PEOPLE- CURRENT USERS (GROUP 1)

- 15.1 The primary care trusts will work collaboratively with the multi agencies and professional involved in the child or young person care including the hospice providers to review all current and existing users.
- 15.2 In the first instance the primary care trust will lead and initiate the reviews and ensure that the child, young person and their family are fully involved with the process. Other relevant agencies who are working with the child and young person will also be involved. Reviews will be undertaken in accordance with national processes implemented locally as per care

pathway in line with assessment processes covered previously in this protocol.

- 15.3 If a professional involved with the child young person and their family report a change in need before the review has been planned then the review will be undertaken as a priority if there are urgent indications.
- 15.4 Reviews of existing service users will be undertaken within 6 months of the contract initiation April 2011, dependent upon the availability of resources.
- 15.5 Reviews will determine that the package of care in place is meeting defined needs and outcomes for the individual child or young person and their family.
- 15.6 Outcomes of the review process will be communicated to the child, young person or their family by the respective primary care trust.

16. REVIEWS FOR NEW REFERRALS WHO ARE IN RECEIPT OF CONTINUING CARE OR JOINT FUNDING AGREEMENTS (GROUP 2)

- 16.1 This group of children and young people differ from the previous group in as much as this group have been defined through local continuing care or aligned budget process as eligible for a package of care of which there maybe a hospice component. The entire package arrangements will be reviewed in line with local processes as previously set down
- 16.2 It should be acknowledged that through the review process, children and young people who are in Group 1 may as consequence have changed needs that place them in Group 2 because they have needs that have been defined as meeting local continuing care or aligned budgets thresholds for eligibility, either because their needs have changed considerably that they require an enhanced package of care or that they have been fast tracked for services under continuing care.
- 16.3 All care packages under this group will reviewed at least 3 months from implementation and then annually to determine that they are meeting the defined outcomes and identified needs, and whether alternative arrangements should be made. If needs change significantly sooner than these timeframes then a review will be initiated.

17. COMMISSIONING REFERRALS TO HOSPICES

- 17.1 Primary care trust commissioners will make referrals to the hospices specifically where the assessment of the child or young persons identified needs, either demonstrate that needs are not being met, or able to be met by existing local services, or that there are no other providers able to deliver the service required; in relation to end of life, or potential end of life, where this can be delivered outside of the core delivery framework of the specification or for short breaks, or where it is in addition to that which can be provided by existing services, a referral will be made.

**18. END OF LIFE OR POTENTIAL END OF LIFE SERVICE DELIVERY
(OUTSIDE OF CORE DELIVERY FRAMEWORK)**

- 18.1 All parties to this protocol acknowledge that in some circumstances end of life care cannot always be provided by the hospices, and that these services sit outside of the core services in the specification.
- 18.2 Commissioners will consult with the hospices on a case by case basis to determine the hospices capacity to deliver this service. It may be possible that this service can be provided collaboratively between the two local hospices or that hospice services can support existing local services. This will be monitored within the data reporting framework detailed within the specification by hospice providers and commissioners.

This protocol will be reviewed annually in to ensure its effectiveness and alignment to local continuing care processes and; quality monitoring of the contract and specification for core hospices services. Reporting data will inform resource gaps analysis and future strategic commissioning needs.

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