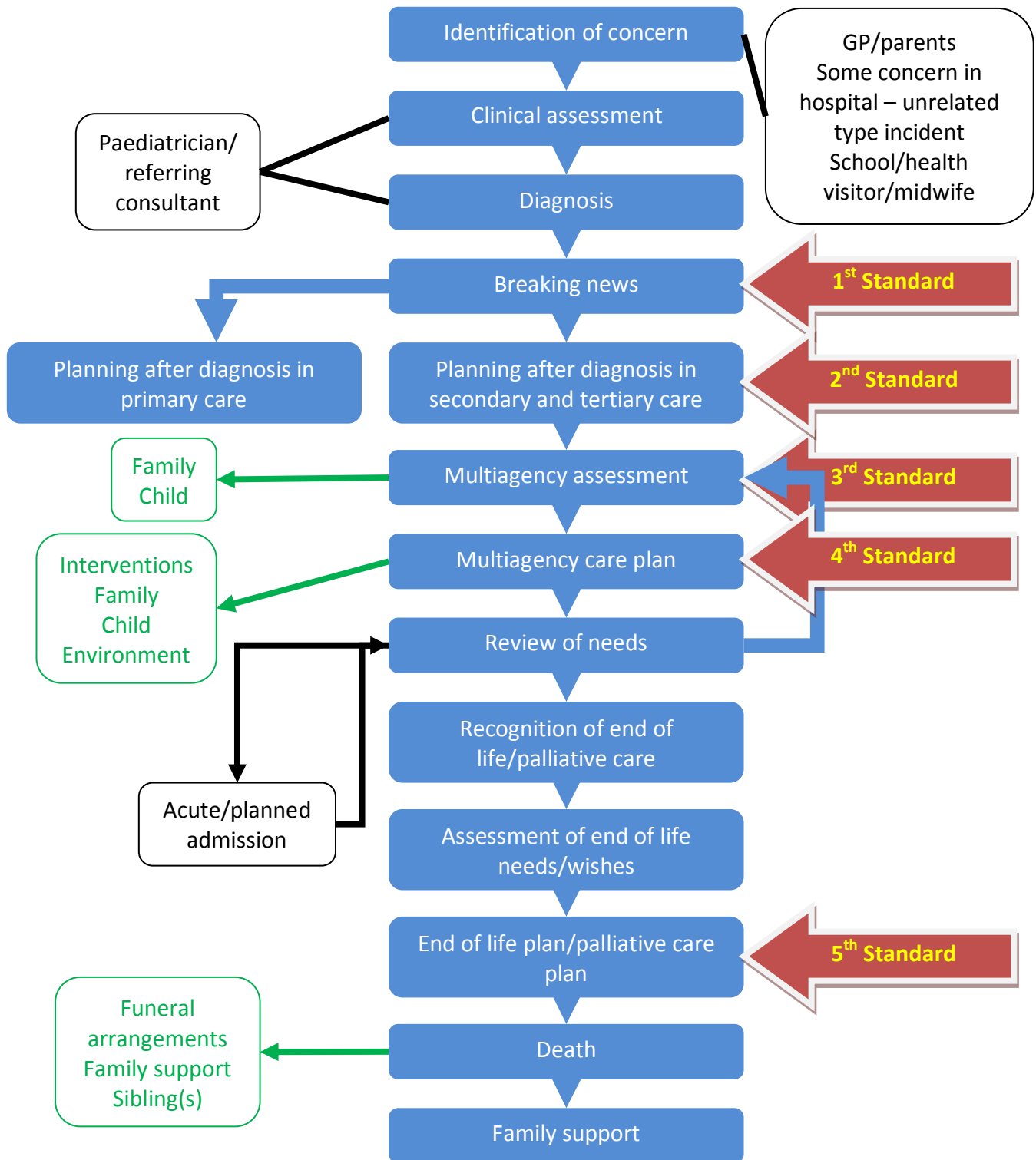


Children's Palliative and End of Life Care Audit Tool

This audit tool has been adapted from the NSF8 audit tool and has many features in common. However, it was felt that a more specific tool was required to reflect the particular needs and strengths of the Yorkshire and Humber region, but more importantly to reflect the care pathway develop by the **Yorkshire and Humber Children's Palliative Care Strategic Group**



As with the NSF8 tool, this audit tool can assist PCTs, and those partner agencies that offer services that are a key part of the integrated care pathway (outlined above) for children and young people needing palliative and end of life care. It can be used in a number of ways:

- gathering information to inform a integrated service review;
- regionally as a benchmarking tool;
- improvement target setting;
- as a basis for obtaining feedback from families on the quality and appropriateness of services offered.

In order to fulfil the above requirement the review and audit tool is best used as part of a process that progresses the development of an integrated service pathway. Analysis of the data from the audit (alongside information from other processes) needs to form part of a collaborative strategic planning process to agree service models, capacity, current gaps and priorities, and to result in an action plan for establishing, with partner agencies and SHA's, appropriate funding and commissioning arrangements.

The audit tool should help the PCT and partner agencies to form a view of how they are meeting the needs of children and young people requiring palliative care. It helps take stock of areas of strength and weakness, and should form part of a process to assist in the development of a multi agency action plan..

We have tried to make the tool as comprehensive as possible so that it can be used in whole or in parts. A full review will give a helpful baseline picture, especially where the audit is undertaken jointly with partner agencies.

We are offering this as a work in progress, and any suggestions for improvement would be greatly welcomed and should be sent to:

Using the Audit tool:

The use of the tool appears superficially simple. It uses a straightforward rating scale and is easy to complete. However, its use will raise a number of complex questions and issues, the solutions to which will improve the wellbeing of children and young people in the final stages of their lives.

The tool uses a 4 point rating scale:

1: No action plan	If there is no action planned to improve the integrated provision of children and young people with palliative or end of life care needs you may be at level one. Typically, at this level you will have: <ul style="list-style-type: none">• no agreed documentation shared by all the agencies covering the appropriate standard/goal;• poor communication between teams;• procedures that are ad hoc and not consistent;• little or unreliable self-evaluation data• no reliable assessment of your performance against this goal.
--------------------------	---

<p>2: Some action taken</p>	<p>If there is an action planned to improve the integrated provision of children and young people with palliative or end of life care needs you may be at level two. Typically, at this level you will have:</p> <ul style="list-style-type: none"> • agreed documentation shared by all the agencies covering the appropriate standard/goal; • improving communication between teams; • clear procedures set out and action to improve consistency; • reliable self-evaluation data • reliable assessment of your performance against this goal with clear and agreed targets for improvement . • Plans for sensitively involving children and their families in shaping your service
<p>3 Action advanced</p>	<p>If you are taking action to improve the integrated provision of children and young people with palliative or end of life care needs you may be at level three. Typically, at this level you will have:</p> <ul style="list-style-type: none"> • agreed documentation shared by all the agencies covering the appropriate standard/goal; • consistently good communication between professionals and teams; • clear procedures which are consistently implemented; • reliable self-evaluation data; • reliable assessment of good performance against this goal with a good record of achieving targets for improvement; • involved children and their families in shaping your service
<p>4: Action has improved outcomes</p>	<p>If you can show you have taken effective action to improve the integrated provision of children and young people with palliative or end of life care needs you may be at level four. Typically, at this level you will have:</p> <ul style="list-style-type: none"> • agreed documentation shared by all the agencies covering the appropriate standard/goal; • consistently good communication between professionals and teams; • clear procedures which are consistently implemented and regularly reviewed • reliable self-evaluation data, regularly collected and analysed with regularly documented monitoring and evaluation ; • A clear monitoring framework involving stakeholders, especially service users • reliable assessment of good performance against this goal with clear evidence of effective service delivery to users in a form they want, when they want it and which improves their quality of life to the highest that can be achieved.

For any areas which you assess as a '4' please give a brief explanation in the comment area provided.

Standard 1 Identification process

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 both the child and the family in language that they can understand.

Key Goal	Rating	Comments (Mandatory for a level four rating, in the absence of evidence a level one rating is indicated) Please cite evidence for your rating
1. Families receive appropriate and sufficient information and emotional care to meet their needs at the point of breaking bad news. Support and follow-up home visits are arranged to ensure that timely, appropriate, accessible and accurate information as well as emotional support is provided to enable children and young people, parents or carers to make choices about the treatment, care and services they wish to use.		
2. Procedures are in place for a comprehensive assessment of palliative care needs to take place in primary (including outreach), secondary and tertiary care as appropriate.		
3. Staff are trained so that information can be provided in an open and honest manner with sensitivity to the emotional needs of the child and their family, in digestible chunks and with time to process.		
4. Facilities are in place so that privacy and dignity is maintained at all times. This will include the availability of appropriate quiet rooms with discrete access		
5. Staff are informed of cultural and faith beliefs and practices so that the individuality of every child, parent and family will be respected. Resources are available so the appropriate language to match the child and family's level of understanding and first language can be used.		

<p>6. Trained and skilled staff are available to discuss prognosis/diagnosis with “vulnerable” parents ie: mental health, substance misuse and parental learning disability.</p>		
<p>7. All communications are documented, circulated to appropriate professionals and a copy is sent to the family</p>		
<p>8. Assessment includes the emotional impact of the diagnosis on the family, including parents’/carers’ relationship with the child. Arrangements are in place to provide emotional support for siblings. This will also include visits to siblings’ schools;</p>		

Standard 2 Planning for secondary or tertiary care discharge with a newly diagnosed palliative care need.

Each child diagnosed in the hospital setting with a palliative care need, should have an agreed transfer plan involving hospital, community services and the family. They should be provided with the resources they require before leaving hospital.

Key Goal	Rating	Comments (Mandatory for a level four rating, in the absence of evidence a level one rating is indicated) Please cite evidence for your rating
1. Procedures are in place so that discharge planning begins at the point of diagnosis.		
2. The hospital will determine a trained named lead professional who will be responsible for initiating the discharge process and initiating the CAF process, incorporating any previous assessments.		

Key Goal	Rating	Comments (Mandatory for a level four rating, in the absence of evidence a level one rating in indicated) Please cite evidence for your rating
<p>3. The lead professional convenes a multi agency discharge meeting should be arranged with the family and appropriate professionals as soon as possible to facilitate discharge this will include details of access to the following locally provided services where appropriate:</p> <ul style="list-style-type: none"> • Training for carers / family before discharge; • 24-hour access to expertise in paediatric and family care (often provided by local community children and young people’s services to enable continuity of care) is available. This is provided directly into the home when appropriate; • Local 24-hour expertise in paediatric palliative care (provided by those with specialist palliative care training) is available; • Pain and symptom control • Psychological and social support • Spiritual support which takes account of the needs of the whole family • Where required, formal counselling or therapy • The timely provision of appropriate equipment • Arrangements to avoid unnecessary emergency admission to hospital are in place • Protocols for immediate access to hospital, if needed, are in place, and • A process for keeping the general practitioner informed and where appropriate ensure training/professional support for a named practitioner in the local GP practice/clinic, • Ensure all professionals are aware of the local SUDIC protocol and <p>A process for informing any department or service expecting the</p>		

Key Goal	Rating	Comments (Mandatory for a level four rating, in the absence of evidence a level one rating is indicated) Please cite evidence for your rating
child at an appointment is notified of death to avoid any 'did not attend' letters being sent out.		
4. Clinicians from the hospital setting should liaise with other agencies to identify the lead professional who will be responsible for co-ordinating the child's ongoing multi disciplinary care plan.		
5. Procedures for monitoring discharge plans demonstrate sustained improvement		

Standard 3 Assessment

Every family should receive a multi-agency assessment of their needs as soon as possible after diagnosis or recognition and should have their needs reviewed at appropriate intervals.

If diagnosis occurs in primary care/outpatients		
Key Goal	Rating	Comments (Mandatory for a level four rating, in the absence of evidence a level one rating is indicated) Please cite evidence for your rating
1. Breaking bad news standards should be utilised at the point of diagnosis		
2. A protocol is in place for children who have a diagnosis made in primary care or outpatients to quickly have a multi-agency comprehensive needs assessment . This should include an assessment of the child and family need in relation to equipment provision, housing, social circumstances and the medical/clinical interventions to meet the individual needs of the child and family for the foreseeable future. The protocol provides guidance on the identification of a key worker		
3. Where appropriate, multi-agency assessments are carried out in convenient settings such as the child's home or school and services are co-located to aid access for families e.g. in child development centres, children's centres, extended schools or one-stop shops.		
4. A multi agency assessment (CAF) will be carried out by the relevant agencies, with basic family data quickly shared between agencies so that this information is only asked for once from the family.		
5. Good practice guidance is available to provider organisations for establishing and implementing the integrated care plan.		

Standard 4 Care planning

Every child and family should have a multi agency care plan agreed with them for the delivery of co-ordinated care and support to meet their individual needs. The Children Act 2004, and the *Every Child Matters/Change for Children Programme* promote the establishment of processes to support integrated provision of services to children, young people and families, through the establishment of the Common Assessment Framework (CAF) and role of the Lead Professional, supported through local children's trust arrangements.

A key worker to assist with this should be identified and agreed with the family.

Key Goal	Rating	Comments (Mandatory for a level four rating, in the absence of evidence a level one rating is indicated) Please cite evidence for your rating
1. Systems are in place to ensure that every child with a critical condition requiring palliative care will have an integrated, multi-professional care plan, signed off by all key agencies, which is resourced and reviewed to reflect the child and family's changing clinical, physical and emotional condition.		
2. There are clear procedures in place for the identification of a key/lead professional as soon as a child is identified as needing multi-professional care.		
3. The key worker service is supported by cross-agency senior management commitment through joint commissioning arrangements.		
4. All professionals have been trained in the use of the CAF which is integrated into individual agencies assessment processes and contribute to an integrated care plan co-ordinated by the lead professional..		
5. There is skilled family support available to enable the family contribute meaningfully to the integrated care plan,		
6. All agencies have clear policies and procedures in place for incorporating the wishes of children and their families into service planning.		

Key Goal	Rating	Comments (Mandatory for a level four rating, in the absence of evidence a level one rating is indicated) Please cite evidence for your rating
7. Care plans are regularly reviewed and systems are in place to ensure that where a child's clinical condition is deteriorating but has not reached an end of life stage the care plan can be rapidly amended for the medical management of increased interventions to support the child.		
8. There are shared accountability protocols for each agency providing services for the family as stated within the CAF to ensure the family's needs are met.		
9. There are protocols in place to allow professional assessments to be shared by all agencies contributing to the integrated care plan		
10. Care plans are formally reviewed and their impacts evaluated. Children and their families contribute to the evaluations which are collated and analysed to inform commissioning and service improvement.		

Standard 5 End of life plan / palliative care plan / advanced directive.

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 as closely as possible.

Key Goal	Rating	Comments (Mandatory for a level four rating, in the absence of evidence a level one rating is indicated) Please cite evidence for your rating
<p>1. Prospective discussion takes place when <u>appropriate</u> with the child and the family regarding end of life decisions including: Resuscitation choices Choice of place of death The withdrawal of non-essential drugs The withdrawal of invasive interventions The subject of organ donation The subject of post mortem. This information is passed on to the local emergency and primary care services.</p>		
<p>2. All children with palliative care needs are monitored to ensure that they have an up to date End of Life plan when appropriate. The plan should be written by the lead clinician involved in the child's care, and reflect their wishes and those of their families. All professionals involved in the care of the child should contribute to the EoL plan.</p>		
<p>3. There are procedures in place to ensure that all professionals caring for, or providing services (including schools and educational services) for the child or their family are aware of the plan's existence or detail and their responsibilities in relation to it. The procedures must be sensitive to the family's confidentiality and privacy.</p>		

Key Goal	Rating	Comments (Mandatory for a level four rating, in the absence of evidence a level one rating is indicated) Please cite evidence for your rating
<p>4. Service planning takes account of the provision of a timely response to any adjustments to the EoL plan. If adjustment to the plan is required due to changes in the child's clinical condition the clinical management plan will be reviewed with the family by either the specialist palliative care clinician or lead clinician and shared with the multi professional team. The EoL plan will be reviewed within time limits determined by the needs of the child.</p>		