



Guidance on
Working with Interpreters
In a
Children's Hospice or a
Palliative Care Setting

This has been developed in association with
Acorns and Rainbows Children's Hospices and with
Together for Short Lives Diversity Reference Group

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Aims of this Guidance

The Translation and Interpretation Services report published by **Children's Hospices UK in 2011** identified that there was a need to provide further guidance on the use of translators and interpreters in a children's hospice context. Some significant gaps in the provision of translation and interpretation services were identified in the 2011 report, but also a great deal of good practice has been captured within this guidance so that it can be incorporated into the development of locally appropriate provision and policies in the setting concerned.

This guidance provides a framework for all children's hospices and palliative care services to utilise and personalise for their individual organisation, and to help them maximise the support they can make available to a diverse range of families.

This guidance is written specifically for children's hospices and palliative care services, but it can be adapted for any health and social care setting.

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1. Introduction

The provision of appropriate access and communication support to users of public services is an issue of equality of opportunity. It also helps combat the effects of racism, social exclusion and the removal of other discriminatory barriers to full participation in society.

The philosophy underpinning this guidance is to ensure that hospice and palliative care services are inclusive of the diverse communities across their locality, enabling equality of access to their services. The guidance aims to increase the level of confidence in the service to enable families, children and young people make informed choices at very crucial and challenging times. Children and families have rights under the Human Rights Act 2000 to be treated fairly and equally and with dignity and respect. The Equality Act 2010 also requires that services are delivered fairly and equally and without discrimination to all who need them.

Interpreting services are a key approach to overcoming communication barriers for a variety of people including:

- Those who do not speak English;
- Those for whom English is not their first language;
- Those who have a hearing impairment or other communication need.

Language difficulties can also affect those who are normally proficient in the use of English, as highly stressful situations often make speaking in a second language challenging. In these situations an interpreter should be provided to ensure effective and sensitive communication.

Using trained interpreters will enable families to interact with professionals so that access to information is provided to help families make informed choices about the type of palliative care that may be provided in the treatment of pain and symptom control, and in other areas such as physical, psychological and spiritual support.

The recommendation within this guidance is to use a professional trained interpreter in preliminary diagnosis and prognosis, to ensure that complicated advice is not misconstrued, creating a situation where the person is unlikely or unable to pursue an available option or service. When a trained interpreter is not available, please see section 6 for guidance on using a friend or relative to communicate with families.

All organisations should have a commitment to equality and diversity, which means that everyone involved within the service has a duty to promote equality, diversity and human rights in the delivery of care to the child/young person and their family and to ensure that everyone associated with the service is treated in a non-discriminatory way.

2. What is the role of the interpreter

The role of the interpreter is to facilitate communication between two individuals. For an effective communication to take place, it is important that the staff, the interpreter, and the agency that provides interpreters are aware of the importance of effective communication in a hospice or children's palliative care situation.

The interpreter should be provided with these guidelines to provide clarity of expectations and links to additional information and terminology regarding the work of the children's hospice or palliative care service.

It is important that the interpreter possesses the requisite qualifications, skills and information to undertake the assignment in a hospice, a palliative care situation, or an end of life scenario.

3. When to involve an interpreter

It is the responsibility of staff members to identify if a situation arises in which there is inequality of access to important information for any member of the family concerned, for example, if an individual is not proficient in English or has communication difficulties. It is also vital to involve an interpreter if an important care/ treatment decision or symptom control and end of life care scenarios are going to be discussed.

4. Safeguarding

Interpreters from an agency will normally be cleared by the Disclosure and Barring Service (DBS), however it is expected that all interpreters will be supervised by a member of staff whether this is face-to-face with the family or during an interpreting session by telephone.

5. Choice of interpreter

It is important to check the family's or individual's first or preferred language or communication method and arrange for an interpreter who is skilled at using that language or communication method. The only exception to this would be in an emergency, when it would be acceptable for the communication to be in a second language which the family and the interpreter have in common. The interpreter should be acceptable to both the staff member and the family. Issues such as gender, age, religion and position in the community should be considered. These should be checked with the individual and the family concerned.

6. Using friends, relatives or untrained interpreters

There are situations in which an untrained person or a bilingual member of staff may serve as an interpreter if a family feels more comfortable with a familiar person, trusted relative or friend. Examples may be in an emergency situation if there is no other option or when dealing with straight forward daily communication.

However, this practice is not a recommended norm especially when discussions with the family concern medical prognosis and treatment, symptom control or end of life care plans.

If the family has requested to use their own interpreter, it is advisable to seek agreement to also include a trained interpreter as appropriate. The role of the trained interpreter is to ensure that both the family and the care staff are receiving accurate information to ensure safety.

Staff should consider the possible risks in using relatives and friends, untrained volunteers or untrained bilingual members of staff to interpret, especially when discussing end of life care or any critical care decisions. These considerations should include:

- Untrained interpreters may not have the depth of linguistic ability in both languages and the knowledge of medical terminology to be able to give accurate interpretation.
- They may want to protect the service user or carer from bad news, or decide to tell them in private later.
- They may not be able to distance themselves from the emotional attachment with the service user and may therefore need the same support as the relative or friend they are trying to interpret for.

- They may withhold information about side effects, believing that it will improve compliance.
- They may answer questions for the individual or carer, without posing the question directly to them.
- They may “filter” information between clinician and family member due to personal concerns or to protect their relative or friend from bad news.
- Family members may interpret inaccurately or withhold significant information (for example because they do not approve of what is being said or because they do not think it is important enough to interpret).

Trained interpreters can provide greater accuracy in interpreting clinical information because they will be fluent in both languages, have knowledge of the medical system and its terminology and are skilled in using various interpreting techniques. They will also be experienced at following an Interpreters Code of Conduct.

Children (under 18years of age) should not be used as interpreters:

- Children are unlikely to interpret accurately because of the lack of fluency in both languages and a lack of knowledge of the medical terminology and may withhold significant information or provide inaccurate versions of what has been said.
- Children could be exposed to disturbing details about terminal illnesses, end of life care, abuse etc.
- Parents/carers may not be explicit about their concerns in trying to protect their children from the information. This could mean the family does not get the help and support they need.
- Children may be expected to keep confidential information 'secret' which is an unfair burden of responsibility for a child.
- Children may divulge confidential information to others which could put the safety of the family at risk.
- Using children as interpreters could damage the relationship between parents and children by giving children an inappropriate role.

7. General code of conduct for interpreters

All interpreters employed via the interpreting agency that the organisation works with must adhere to the Interpreter’s Code of Conduct. This should be shared with the interpreter as part of the pre briefing. An example Code of Conduct for Interpreters is provided overleaf:

General Code of Conduct for Interpreters

Skills

In order to work reliably and effectively, interpreters working within a children and young person's hospice or palliative care service must have:

- A good command of English/sign languages as well as the individual client's language.
- A familiarity with and an objective understanding of the culture(s) in question.
- An awareness of the sensitive nature of the services provided by children's hospices and palliative care services.
- Competence in the relevant interpreting and translation techniques.
- An ability to function professionally in all situations.
- A commitment to the National Register of Public Service Interpreters' professional Code of Conduct and Guide to Good Practice.
- A sound knowledge of the structure, procedures and commonly used terminology of the hospice and palliative care sector in which they are contracted to work.
- Complete impartiality of attitude, speech, and script.

Impartiality

- The interpreter will not negotiate or advocate on behalf of either party.
- The interpreter will not act as advisor or counsellor for any party.
- The interpreter will not attempt to influence the outcome of any exchange between parties.

Confidentiality

- The interpreter will maintain utmost confidentiality and trust, since clients need to feel that total discretion will be observed by both the interpreter and the agency.

Awareness of professional limitation

The interpreter has the right to refuse an assignment in the following circumstances:-

- If he/she feels that they have been inadequately briefed.
- If he/she feels that they do not have adequate training or support or information about the structure, procedures and commonly used terminology of the hospice and palliative care setting in which they are contracted to work.
- If she/he is subject to unacceptable demands or behaviour from clients.

Equal opportunities

- An interpreter will not discriminate between parties, either directly or indirectly, because of their gender (including sex, pregnancy, parental status, and gender re-assignment), race (including ethnic origin, colour, cultural identity, nationality and national origin), disability, marriage and civil partnership status, sexual orientation, religion or belief, age or social or economic class.

Cultural guidance

- The interpreter may, as a separate discussion, give guidance on cultural norms and differences, in order to facilitate fuller understanding between parties. This is done, however, in the recognition that it is the view of the individual interpreter and that no individual can speak for a whole culture or race.

Sensitivity

- If the assignment has been accepted, the interpreter will also be required to demonstrate sensitivity and understanding in coping with tense and stressful situations, such as end of life care, palliative care, bereavement, and safeguarding concerns.
- Similarly, consideration by the hospice or palliative care service will also be given to the sensitivities of the interpreter and his/her exposure to such situations.

An example of an individual service's (Rainbows) Code of Conduct for Interpreters is attached at Appendix 1.

8. Confidentiality

All interpreters should be aware of their responsibilities with regards to confidentiality and data protection.

Should a qualified volunteer interpreter be utilised, they will be required to sign a confidentiality agreement. See Appendix 2

9. How to involve an interpreter

The services of an interpreter may be utilised in different ways; e.g. face to face, in meetings or via the telephone as a three way conversation, as appropriate.

The need for interpreting services may be planned, for instance as part of care planning and review, or may arise in an emergency, for example in an end of life care scenario.

All services should have in place clear protocols and procedures outlining the key roles and responsibilities for the identification, approval and payment process for arranging interpreting services in both planned and emergency situations.

An accessible list should be kept by the hospice or palliative care service of appropriate local interpreting services and qualified volunteer interpreters and staff. Staff who are bilingual or

who have signing skills may also record this information so these can be utilised in day to day communication matters with children and families.

10. Pre meeting briefing with the interpreter

It is essential for the staff member and the interpreter to agree the basis on which they will work together before the interpreting process starts. Issues to clarify are: the organisation's requirement, the family situation, and the sensitivities expected.

It may be useful to discuss the style of interpreting which will be used and the format and purpose of the meeting with the family.

The interpreter should be issued with a hospice information leaflet in plain English/Makaton and the relevant community language if available. See Appendices 5 & 6..

11. During the meeting with the family

The staff member should pace the conversation to ensure that the interpreting can take place effectively. They should be prepared to clarify terms or difficult concepts in order to help the interpreter be as accurate as possible. Appropriate time should be allowed for effective and full interpretation to take place. It is also important to allow for pauses in the interpreting process, to allow families to absorb difficult information and ask questions.

Owing to the sensitive nature of children's palliative care situations, the interpreter will be expected to interpret verbal communication, along with conveying emotional or difficult news, between staff and families. The interpretation needs to reflect the attitude of staff and values of the organisation in supporting families through traumatic situations.

The interpreter has a role in ensuring that each person's reactions and feelings are made explicit and that the family members' differences of view, disability, culture, relationships, and beliefs are understood.

The interpreter should make appropriate interruption if, for example, the individual or the family is failing to understand certain words or concepts, or if the interpreter feels that what is being asked or advised is discriminatory, insensitive or inappropriate.

12. Debriefing with the Interpreter after the meeting

The staff member should allow time for discussion and debrief with the interpreter to express his/her views. This may include assessment or clarification along with emotional support for the interpreter in case of a particularly stressful interview. This can be provided by the staff member.

If the meeting with the family and the interpreter has not been successful, the member of staff should discuss this with their manager.

13. Guidelines for Chairs/facilitators on using interpreters in meetings

The task of chairing a meeting using an interpreter is complex and needs to be well planned. The Chair should arrange to meet the interpreter in advance of the meeting to explain the objectives and format of the meeting and to agree with the interpreter how they will work together. This obviously depends upon the needs of the family who require interpretation, the type and formality of the meeting and the skills and training of the interpreter. Particular consideration needs to be given to the style of interpretation to be used in the meeting. (See Appendix 3)

In the introduction to the meeting, the Chair should outline the role of the interpreter and the style of interpreting to be used. The Chair should also state that no comments should be made in the meeting that participants do not want to have translated.

Depending on which interpreting style is to be used, the Chair should:

- Halt the meeting at frequent enough intervals for the interpreting process to take place
- Be prepared to clarify terminology or difficult concepts used by participants in order to help the interpreter to be as accurate as possible.
- Ensure that everything that is being discussed in the meeting is interpreted to the family/individual, even though the conversation might not be directed at them.
- Ensure that the family is given plenty of opportunity to respond through the interpreter.

14. Checklist for engaging and working with interpreters

- Identify any language barriers.
- Identify who has the language barrier - the child, young person, mother, father, carer/guardian?
- What language do they speak (for language identifier see Appendix 5)
- Inform appropriate manager of the need for an interpreter following local processes for approval for either planned or emergency situations
- Decide the type of interpreting that is required to meet the needs (see Appendix 3 on styles of interpreting)
- If appropriate, assess if a qualified member of staff or volunteer is available
- Agree and arrange date, time and location as required by the family.
- Refer to the interpreting agency contract and contact the agency.
- Hold briefing session with interpreter to explain the circumstances, this could include a tour of your building detailing the services that you provide, type of interpreting to take place, needs and sensitivities.
- Ensure that documentation has been made available.
- Set aside adequate time for the interpreting session
- Following the interpreting session, debrief the interpreter. This should include how they feel the session has gone, any cultural inference which should be taken into account, and the wellbeing of the interpreter.
- In the situation of a telephone session, phone back following the session to debrief.
- Sign the timesheet of the interpreter
- Record that the service has been used and the level of satisfaction of the session, any outcomes and follow up required

15. References

Translation and Interpretation Services; March 2011, Children's Hospices UK

'Guidance handbook for Acorns Staff on Working with Interpreters' October 2004, Acorns Childrens Hospice.

Rainbows hospice information leaflets and translations
<http://www.rainbows.co.uk/the-hospice/translations/>

Acorns Children's Hospice Guidance on Interpreters

Rainbows Hospice Policy and Procedure for Staff on Engaging an Interpreter

East London and the City NHS (Mental Health NHS trust)

Institute of Linguists
<http://www.iol.org.uk>

Code of Conduct for Interpreters at Rainbows

When working for a children's hospice, it is important that interpreters are aware of the sensitive nature of the work undertaken to deliver excellent palliative, end of life and bereavement care for children, young people and families.

To be able to facilitate a sensitive and accurate communication in a hospice situation, it is important that the organisation's Code of Conduct for Interpreters is followed, i.e.

- That the interpreter has an excellent spoken command of English and be fluent in the interpreted language, including any specialist terminology, idioms or dialects
- That interpreters will always ask for clarification, disclose any difficulties they may encounter regarding dialects or medical, technical or hospice jargon terms, and if these cannot be satisfactorily remedied, withdraw from the assignment
- Use appropriate techniques such as consecutive interpreting, simultaneous interpreting and sight translation to interpret accurately and fluently. (See Appendix 3, Styles of Interpreting)
- Understand the required procedures and context for working in a hospice. Additional resources and documents are signposted in these guidelines
- Respect the family's customs, values and spiritual beliefs which may be different to your own. Personal opinions and beliefs should not influence the situation
- Interpret in the first person truly and faithfully what is said, without anything being added, omitted or changed, and to be able to provide a summary if requested by both parties
- Not enter into the discussion, give advice, or express opinions or reactions to any of the parties.
- Intervene only
 - To ask for clarification
 - To point out that a party may not have understood something
 - To alert the parties to a possible missed cultural inference
 - To ask for accommodation for the interpreting process
- When intervening, ensure that it is done in a sensitive and transparent manner so that both the staff member and the service user clearly understand the nature and relevance of the intervention or communication.
- Not delegate work, nor accept delegated work, without the consent of the agency

The organisation expects interpreters:

- To indicate clearly and unequivocally, at the initial contact, if he/she is available to undertake the assignment and if she/he is able to accept the nature of the task
- To have an excellent spoken command of English and the interpreted language, including any specialist terminology, idioms or dialects

- To be reliable and punctual at all times; The interpreter to contact the organisation immediately if, for any reason, they are running late, or are unable to attend, an assignment
- To always dress appropriately for an assignment to meet business and cultural needs
- To inform the agency immediately if they do not feel comfortable with the issues being discussed or if they believe that they are not competent to undertake the assignment
- To respect confidentiality at all times and not seek to take advantage of any information disclosed during their work
- To interpret in a culturally sensitive way, both in words and in manners
- To be objective but in a sensitive manner, making sure that he/she interprets not only the spoken words but also expresses the empathy and sensitivity conveyed by the organisation's staff, through the use of tone, pace and manner.
- To be able to interpret the anxiety and concerns expressed by the child, young person, and family to staff members
- To disclose immediately if the interviewee or immediate family is known or related to the interpreter
- To act in an impartial and professional manner
- To not discriminate against parties, either directly or indirectly, because of their gender (including sex, pregnancy parental status, and gender re-assignment) race (including ethnic origin, colour, nationality, and national origin), disability, sexual orientation, marriage and civil partnership status, religion or belief, age, or social or economic class.
- To disclose any conflict of interest that they may have regarding business, financial, family or other interest in the matter being handled.
- Not accept any form of reward, whether in cash or otherwise, for interpreting work other than payment by the employer
- Ensure that any notes taken are left with the Hospice or service or destroyed on site
- Have all claim forms signed by the Hospice member of staff, using the interpreter to verify the actual hours of interpreting carried out

In return, the organisations staff will:

- Before the assignment, familiarise the interpreter on the general nature of the hospice's work, and in particular, advise on the depth of interpreting, beyond language alone
- Before meeting the family/individuals concerned, explain the circumstances of the family's situation so that the interpreter can deal with the communication accurately and sensitively
- Set aside adequate time for effective interpretation to take place
- Debrief the interpreter at the end of the session.

Undertaking of Confidentiality

Paid Interpreters, as well as qualified volunteer interpreters at (name of organisation) hospice are expected to adhere to rules of confidentiality and data protection.

You are required to sign a written undertaking that you will:

- Inform the member of staff, before the interpreting process begins, if the family is known to you (and also accept that it is the family's right to have the interpreter of their choice).
- Not divulge any conversation or exchange of information that takes place during the interpreting process without the permission of the staff member involved.

I accept and agree to follow the confidentiality and data protection guidelines indicated above

Full Name:

Signature:

Date:

Name of Agency:

Styles of Interpreting

Consecutive interpreting

Most community language interpreters will undertake consecutive interpreting – that is, they will wait until the speaker has finished before they begin interpreting. Staff members will, therefore, need to be aware of the need to pause from time to time during longer pieces of speech so as to keep the task manageable for the interpreter.

Simultaneous Interpreting

It provides an instant interpretation of what is being said. Speakers do not have to pause to allow the interpreter to speak which means that conversations can flow more naturally.

Whispering interpreting

Often combined with consecutive, this style of interpreting is typically used for interpreting to an individual where there is only one foreign language involved. As the name suggests, this approach does not require any equipment and involves the interpreter whispering the interpretation to the individual during the meeting or visit.

Telephone

This is also referred to as over-the-phone interpreting. This enables the interpreter to deliver interpretation via telephone on a conference call. Telephone interpreting may be used in place of on-site interpreting in some cases, especially when no on-site interpreter is readily available at the location where services are needed.

Google Translate

Google Translate is a free translations service that provides instant translations between 57 different languages. It can translate words, sentences and web pages between any combinations of its supported languages. Google Translate can be accessed via the web and on many websites. Google TM Translate is a free, automated service that relies on data and technology to provide its translations. It provides literal translations and may not take into account cultural norms and subtleties. An automated translation has limitations and it is not intended to replace human translators, especially in a children's Hospice or palliative care environment.

Verbatim translation/interpreting

This is sometimes also referred to as word-for-word or literal translation/interpreting, and linguists will usually understand this to mean the production of a close, faithful and accurate version of the original in the target language.

Sign Language

The act of interpreting is when a hearing person speaks; an interpreter will render the speaker's meaning into the sign language, or other forms used by the Deaf party and vice versa, when a Deaf person signs, an interpreter will render the meaning expressed in the signs into the oral language for the hearing party. This may be performed either as simultaneous or consecutive interpreting. Skilled sign language interpreters will position themselves in a room or space that allows them to be seen by the deaf participants and heard clearly by hearing participants.

Some useful definitions

Translation

The conversion of written text from one language to another.

Interpretation

The conversion of speech from one language (including British Sign language and other sign languages) to another. Interpreting may involve the conversion between two live spoken or signed languages or between a spoken language and a sign language.

Communication Support

A variety of forms of support and communication with those who do not use the conventional forms of spoken or written English, including Braille and other tactile forms of writing, lip reading and lip speaking and various communication technologies.

Accredited Interpreters and Assessing their Work

Language interpreting and translation skills should always be checked before employment is offered. Public bodies procuring interpreting and translations services should ensure that appropriate quality assurance processes exist. These should include a sample proof reading of translated material and the occasional recording and checking of interpreting work.

Advocacy

This implies being on the side of, or speaking for, a particular party, or otherwise aiming to support, protect, advise or further the interests of a particular individual or group. To act as an advocate can be in direct conflict with the interpreters' code of ethics, which requires interpreters to be unbiased and impartial in their work.

Additional Language

A language which someone may have acquired or learned, but which is not their "first" language i.e. their home language or the language in which they are most proficient and comfortable.

Approved qualifications

Bilingualism is an essential element of proficiency in interpreting. An interpreter however, also has to have knowledge of the organisation's environment and operating processes, the ability to cope with specialist vocabulary and an understanding of the rights and responsibilities of the public service interpreter. The best way to acquire such proficiency is through high quality training. Successful completion of the Diploma in Public Service Interpreting (DPSI) provides interpreters and translators with the only professional certificate of competence currently available in this field. Those who have gained a DPSI can ensure service users that they are working with qualified staff trained to nationally recognised standards.

Best Value

The provision of accessible communication arrangements promotes best value by ensuring that all public bodies are open, transparent and accountable organisations. Appropriate communication support ensures a customer/citizen focus to the delivery of services.

Bilingual Worker

A bilingual worker is someone who has the language skills needed to carry out the tasks required by their work in either the official language of the country (e.g. English) or in another language (e.g. Urdu or French). This means that they can function as a care worker, doctor or as a counsellor in at least two languages. This does not mean that they have the skills required to work as a translator or interpreter between these two languages on behalf of two other interlocutors.

Brailing of Documents

Braille is a writing system consisting of raised dots which people can read by touch. Braille translation software can be used in-house and documents printed off on a Braille printer (embosser), but most work is produced by professional transcription agencies.

Briefing Interpreters

Organisations should respect the role of the interpreter. Pre-meetings could be used to clarify respective roles, to provide briefing about the background and practical purpose of the interview or assignment and to deal with issues such as confidentiality and positioning. The organisation should also ensure that the interpreter is clear about the use of technical terms or specialist vocabulary.

Care of the Dying

Care of the dying is the care of the patient and family in the last hours and days of life. It incorporates four key domains of care: physical, psychological, social and spiritual care, and supports the family at that time and into bereavement.

Child

A child is defined as a young person aged up to their 19th birthday.

Children's Hospice Services

Children's hospice services provide palliative care for children and young people with life limiting conditions and their families. Delivered by a multi-disciplinary team and in partnership with other agencies, children's hospice services take a holistic approach to care, aiming to meet the needs of both the child and family –their physical, emotional, social and spiritual care – through a range of services.

These include:

- 24 hour end of life care
- Support for the entire family (including siblings, grandparents and the extended family)
- Bereavement Support
- 24 hour access to emergency care
- Specialist short breaks
- 24 hour telephone support
- Practical help, advice and information
- Provision of specialist therapies, including physiotherapy, play, and music therapy
- Provision of information, support, education and training to carers, where needed
- Children's hospice services deliver this care in the home (commonly termed 'hospice at home service') and/or in a purpose built building

Children's Palliative Care

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements of care through to death and beyond. It focusses on enhancement of quality of life for the child/young person and support for the family, and includes the management of distressing symptoms, provision of short breaks, and care through death and bereavement.

Complex Care/Continuing Care

Complex or continuing care is a bespoke package of care beyond what is available through core and universal services. It is provided to children with high levels of complexity or intensity of nursing care needs.

Disclosure

The National Register of Public Service Interpreters' Code of Conduct and Guide to Good Practice states, under 'Ethical and Professional Issues', that interpreters disclose any information, including any criminal record, which may make them unsuitable in any particular case. Interpreters may find themselves working in positions of trust, such as assignments involving children or vulnerable adults. In the interests of public safety, interpreters should be prepared to agree to appropriate searches being carried out by the Disclosure and Barring Service (DBS).

End of Life

The end of life phase begins when a judgement is made that death is imminent. It may be the judgement of the health/social care professional or team responsible for the care of the patient, but it is often the child/young person or family who first recognises its beginning.

End of Life Care

End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focusses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both the child/young person and the family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms, and provision of psychological, social, spiritual and practical support, and support for the family into bereavement.

End of Life Care Services

End of life care services are services to support those with advanced, progressive, and incurable illnesses, to live as well as possible, until they die. These are services that enable the supportive and end of life care needs of both the child/young person and the family and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. This is not confined to discrete specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting.

Equality of Opportunity

The provision of appropriate access and communication support to users of public services is an issue of equality of opportunity. It also helps combat the effects of racism, social exclusion and the removal of other discriminatory barriers to full participation in society.

Family

The term 'family' includes parents, other family members involved in the care of the young person, or other carers who are acting in the role of parents. Family includes informal carers and all those who matter to the child/young person.

Face to Face Interpreting

This is when the interpreter is physically present in the room. It is usually "bilateral" interpreting, a term used to describe the type of interpreting when the interpreter is working "in both directions" between two languages i.e. both into and from their preferred language (or "mother" tongue). This type of interpreting is often used in situations involving meetings, interviews or visits.

First or Preferred Language

This may be the first language learned by a person at home ("mother" tongue) or the language in which they are most proficient or feel most comfortable.

Funding

Organisations should make arrangements to ensure that sufficient funding is available for the engagement of professional interpreters, all forms of communication support and the translation of

information as appropriate. In circumstances where organisations rely upon family members or friends to provide an informal interpreting service they should ensure that adequate checks and balances are in place. When applying for external funding for specific projects, the issue of communications support should be resourced along with other access criteria.

Hands-on Signing

This method of communication involves using British Sign Language. The Deaf blind person follows the signs by placing their hands over the hands of the signer.

Hospice for Children and Young People

Hospices provide short breaks (a few days away from home) tailored nursing care for each child, emergency and end-of-life care, and bereavement support. It provides a range of specialist services which can benefit the children and young people themselves and the wider family.

Hospice at Home

Hospice at Home is a term commonly used to describe a service which brings skilled, practical children's palliative care into the home environment. Hospice at Home works in partnership with parents, families and other carers.

Human Rights

The Human Rights Act 1998 envisages the right to information in a language that a person understands when he/she is subject to legal processes. All public authorities should recognise the rights of those who live in our multi-lingual and multi-cultural society to understand, to be understood, and their need to express themselves according to their own linguistic and cultural norms and values.

Key Working

Key working or care co-ordination is a service, involving two or more agencies, that provides disabled children and young people and their families with a system whereby services from different agencies are co-ordinated. It encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels, and a named key worker for the child and the family. Families with disabled children should only have a key worker if they want one. (Care Co-ordination Network UK 2006)

Life Limiting/Life-Shortening Conditions

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer. Children in long-term remission or following successful curative treatment are not included.

Lip-reading

This may be a form of communication used by deaf people who use English as one of their communication choices. It is reported that around 40% of what is actually said is captured by the deaf person.

Makaton

This is a created communication system comprising speech, manual signs and graphic symbols to assist people with communication difficulties, especially learning difficulties.

Needs-Led

Need-led is the term used to describe how services should be provided on the basis of the needs of the patient and family and not as a result of assessing the resources that are available. To deliver a needs-led service it is important to assess and thoroughly understand the needs of the children, young people and families first.

Needs of the Service Users

When accessing communication support, the needs of the individual client are paramount. Staff should take steps to ensure matches for language and dialect and that gender issues are addressed.

This is of particular, but not singular, importance to Muslim women. Constant evaluation of interpreting assignments is important to gauge that the individual needs are being met.

Note-taking

Note-takers often work for Deaf people in meetings or in lectures. These notes may be handwritten, or increasingly, taken in electronic format (cf. Speed Text). The notes may be for reference at a later time, or a deaf person may read off the computer screen in real time. The notes taken will not be verbatim.

Palliative Care

This is the active total care of patients whose disease is not responsive to curative treatment and includes any care that alleviates symptoms while embracing, psychological, physical, social, cultural and spiritual aspects of a patient's care. Medical care needs may include managing pain and controlling symptoms.

Parents

The term 'parents' is used to mean any carer for a child whether that is a married or unmarried couple, a single parent, guardian or foster parent.

Primary Healthcare Team

A primary healthcare team comprises the general practitioner (GP), practice nurse, and community staff (such as community children's nurses or physiotherapist) who work with the practice staff.

Respite care

This is an outdated term for Short Breaks. See short breaks

Service Level Agreement

A service level agreement is an agreement between the commissioner and any organisation providing a service. They specify standards to which the service should be provided, for what sum of money and for how long.

Short Breaks

Short break care has three main functions:

- To provide the child or young person with an opportunity to enjoy social interaction and leisure facilities
- To support the family in the care of their child in the home or an alternative community environment such as a children's hospice
- To provide opportunities for siblings to have fun and receive support in their own right

Short breaks may offer the whole family an opportunity to be together and to be supported in the care of their child or it may offer care solely for the child or young person.

Specialist Short Break Care

Specialist short break care refers to a setting of care, a programme of care, or a service that provides additional care for highly complex or technology dependent children who may otherwise be excluded from short breaks provided by social care. It may take place in the child's home or in a setting outside of the home such as a hospital, long-term care facility or hospice. Specialist short break care provides the support required to meet the child's holistic care needs and enables children and families to access short break services. Specialist short breaks will often address some aspects of symptom management. Specialist short breaks should also meet the functions described under general short breaks.

Supportive Care

Supportive care is an 'umbrella' term for all services, both generalist and specialist, that may be required to improve the quality of life for people with life-threatening illnesses. It recognises that people need some forms of care that are not directed.

Symptom Management

Symptom management is the management of common symptoms associated with life limiting conditions. It is often used to refer to symptoms that are primarily physical, but in palliative care, symptom management also includes attention to psychosocial and spiritual aspects of symptoms where appropriate.

Technology Dependent Children

Technology dependent children are those who need both a medical device to compensate for the loss of a vital bodily function and substantial and on-going nursing care to avert death or further disability.

Transcription

A transcription is often a verbatim written record of spoken language material and of material in certain signed artificial communication systems based on the same language (for example, sign supported English, SSE, or Signed Exact English, SEE). A transcription is completed working from recorded material and involves the transfer of material in the same language between different media, spoken to written, signed (manual coded system) to written, rather than transfer between different languages. Transcription may also be used to describe transfer into audio or other formats (e.g. Braille, large print, and electronic version) for blind people or people with literacy needs.

Young Adult

The term young adult describes a person from their 19th birthday.

Young Person

The term young person describes a person from their 13th – 19th birthday.

Language Identifier

In order to ensure effective communication takes place it is important to be clear what is the family's or individual's first or preferred language. This is sometimes difficult when you don't know where a family are from or what language they speak.

To help with this identification, Rainbows have adopted the Pearl Linguistics' "Language identifier". This can be accessed at <http://www.pearllinguistics.com/language-identifier>

This enables the family or individual to point out their country's flag and the language can be identified audibly from those listed under the flag.

Plain English Leaflet on Rainbows Hospice

The Plain English leaflet on Rainbows Hospice can be downloaded at

www.rainbows.co.uk/info

This leaflet in Plain English is also available in Sign, Large Print, Braille and 16 community languages, which are also available from the above web link.