

# **HANDLING DIFFICULT NEWS IN PAEDIATRICS**



## **COURSE WORKBOOK**

**All-Wales Paediatric Palliative Care Network**  
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## Introduction

This Course Handbook has been designed to accompany a series of workshops across Wales entitled 'Difficult Conversations at the End of Life for Children'. The Handbook is structured in the same way as the workshops, with half focusing on communication skills and the other half on how to use the Paediatric Advance Care Planning tool (PAC-Plan).

The communications skills section of this book comprises an introductory section on communication skills within paediatrics generally (including written communication), and a second section on two of the most useful rubrics for communication in palliative care; the Cardiff Toolkit and the SPIKES tool.

The PAC-Plan section comprises an introduction to the nature and purpose of advance planning in children, the PAC-Plan documentation itself and lastly the policy that supports it. For historical reasons, the Plan and the policy were originally developed and approved in Cardiff and the Vale ULHB before being adopted in each of the other LHBs in Wales. In the process of adopting them, each of the LHBs has made some modifications but they have usually been small (such as a different logo or telephone number).

### *Acknowledgements:*

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The section on communication tools was written by Dr Tim Warlow, specialist trainee in paediatric palliative medicine in the Wales Deanery. The section on practical use of the PAC-Plan was written by Mrs. Kath MacSorley, Paediatric Palliative Care Nurse Specialist for Cardiff and the Vale.

Development of the PAC-Plan was over many years and the number of people who were involved during that time is too great to mention all their names. The project was led at different times by Dr Jo Griffiths (Consultant in Community Paediatrics in ABMUHB and Paediatric Palliative Medicine in the all-Wales Network), Dr Michelle Jardine (Consultant in Paediatric Intensive Care in Cardiff and the Vale) and Dr Richard Hain (Consultant and Clinical Lead for the all-Wales Network in Paediatric Palliative Medicine).

The cover was designed and drawn by Dr Katy Smith, trainee in Community Paediatrics in the Wales Deanery with a special interest in palliative medicine.

## Table of Contents

<b>Introduction .....</b>	<b>2</b>
<b>Table of Contents.....</b>	<b>3</b>
<b>Section 1: Communication.....</b>	<b>4</b>
Introduction .....	4
Basic science .....	5
Summary .....	12
Communication with colleagues.....	12
Summary .....	16
Goals of communication.....	17
Communication Skills Tools .....	20
The Cardiff six-point toolkit.....	20
SPIKES – A six step protocol for delivering bad news.....	22
<b>Section 2: Advance and emergency care planning .....</b>	<b>25</b>
Introduction .....	25
Who speaks for the child ? .....	25
The problem: different agendas, different timescales .....	26
What the PAC-Plan is .....	27
What the PAC-Plan is not.....	29
Summary .....	30
PAC-Plan in practice.....	31
Who should complete the PAC plan? .....	31
When to complete a PAC plan. ....	31
Starting the process. ....	31
Further discussions. ....	32
Who to share the document with. ....	32
Additional documentation. ....	33
The PAC-Plan document itself .....	34
Policy.....	45

## Section 1: Communication

### Introduction

*Richard Hain*

*John Hain*

The medical care of children is perhaps unique in the extent to which it relies on collaboration with the family. When considering a treatment plan for children, paediatricians take it for granted that the child's parents will always be available to the child, that they will usually have the child's best interests at heart, and that they will be able to work alongside medical and nursing staff. In effect, parents are expected to be colleagues with the paediatric team.

If this collegiate relationship is going to work safely and effectively, it is essential that families feel both confident and competent. It is the aim of communication with patients and their families to facilitate this, both by imparting information and by encouraging confidence. In many conditions, particularly those that persist for many years, families will come to see themselves as experts not only in their individual child, but also their child's condition. At the time of diagnosis, however, it is important to be able to impart not only facts, but an understanding of them, in an effective manner.

Factors that can make this more difficult include prior understandings (and misunderstandings), emotional coping mechanisms such as denial, and simple differences in the way information is given and received, such as vocabulary. It can be complicated by difficulty in remembering information. Devices for helping memory, such as audio recordings, diagrams or hand-written notes, are all important.

The aim of this chapter is to consider some of the ways in which communication can be practically facilitated in order to reduce the chance of misunderstanding, and to optimise effective transfer of information and understanding, not only from doctor to family but also from family to doctor.

## Basic science

The commonest communication scenario is in a situation where the doctor is expected to impart news or information. It is often the situation in which doctors feel most comfortable. There are always communication needs beyond simple information transfer, however, many of which the doctor will be unaware of but which will inevitably complicate the discussion if they are not acknowledged.

In general, in any communication the doctor has two responsibilities to the family and patient. The first, and the simplest, is simply the passing on of information that the doctor has and the family needs. This needs to be done clearly and honestly.

The second, more nebulous but often more important, is to ensure that the family feels 'valued' by the professional. There is a power imbalance inherent in the relationship between doctor and patient since the doctor has the knowledge and is in his or her own environment. One of the goals of good communication exchange is to redress this imbalance.

This is more than good manners; the family or patient that feels their concerns have not been understood or taken seriously are less likely to work well in the team. Difficult though it can be, imparting this sense of being valued to families and patients is of practical importance in ensuring good patient care. Empathy – not only a capacity to understand something of what they are going through, but an ability to communicate back to the family that you have understood it – is a highly effective way to ensure this sense of being valued.

With this in mind, the process of giving news or information can be considered in five stages:

### 1. Setting the scene

Communications should take place in an environment that is conducive to the exchange of information. This needs planning. Of course it is not always possible and communication may at times have to be impromptu, but this should usually be avoided, if necessary by arranging a discussion at a specified later time.

Most families find discussions with healthcare professionals, and particularly doctors, quite intimidating and will need positive encouragement to volunteer information. The aim of setting the scene is to provide a physical and temporal space in which communication is facilitated.

- **Physical space.** Privacy is essential if families are to feel comfortable discussing important issues. Discussions should ideally be in a quiet room reserved for the purpose, whose door can be shut to ensure privacy. The room should be comfortably furnished. Sofas and armchairs are preferable to institutional chairs, and have the advantage of allowing professionals and family to be on the same physical level.
- **Temporal space.** It is important for families that they feel the doctor has put some time aside specifically for them. An unhurried atmosphere can allow more efficient information exchange so that discussions can be shorter without sacrificing effectiveness. Creating this 'space in time' is, paradoxically, a time-saving manoeuvre.

Mobile phones and bleeps should be switched off or handed to someone outside the room so that the risk of interruption is minimised. Not only does this reduce the risk of interruption, it also sends the message to the family that for this period of time their concerns are the most important. It is important to avoid consulting a watch during the discussion as this will give an impression of hurry.

- **Removing barriers.** It is common for doctors unintentionally to discourage contributions from families they are interviewing. A positive effort may need to be made to remove barriers. An obvious example is the physical presence of a desk separating two people having a discussion. Eye contact on the same level is important as it emphasises equality rather than power differential. Doctors should avoid standing while the family sits, or sitting in higher chairs. Eye contact should be maintained. It can be difficult to hold someone's gaze when breaking bad news, but it is very important. The assumption made by many people if eye contact is lost is that information is being withheld, or that the doctor is not being entirely truthful. This sense of evasiveness is a powerful conviction which, once held, can be very difficult to change.
- **Having the facts straight.** It is important to realise how much importance is attached by families to discussions with doctors. Where there are results to be communicated to the family, it is essential that it be done accurately. Ideally, it is helpful to have the relevant reports printed in front of you. If this is not possible, it is preferable to admit uncertainty than to discuss a half remembered result.
- **Who else should be there?** A counsel of perfection is that both parents should be present when discussions of any significance take place. This is both for their mutual support, and to minimise the risk of misunderstanding between them when information is relayed.

In practice, this is not always possible. An alternative is to arrange a second interview to cover the same ground, or to make an audio recording that can be handed to the spouse.

If these discussions are taking place on a ward where the child is or will be admitted, it is a good idea to ensure that one of the nursing staff from the ward are present. This allows the family to identify a more accessible information resource to whom they can turn once they have had time to digest the conversation and need to ask further questions. It is also a good opportunity to support nursing colleagues and to emphasise that you are part of the same team. This can be reassuring for families when everything else seems disturbing and new.

## 2. Alignment

It is tempting to start the discussion with what we want to say, but this would be like aiming a gunshot without first looking at the target. Instead, the first stage should be to establish what the family already knows or understands by inviting them to talk first. Alignment essentially means getting some idea of what things look like from the family's perspective. In aligning him- or herself with the patient, the doctor should gain an understanding of:

- **What they have already been told.** Many families will have considered leukaemia, perhaps because it has been mentioned as a possibility by the referring GP or other doctor. Others will have no idea this is a possibility, while some will be afraid to mention their fear of it.
- **Any prior experience and its impact.** Leukaemia in childhood is cured in around 75% of cases. Most families who have considered it as a possibility will extrapolate from their own knowledge of cancer, which are usually in adults and carry a much worse prognosis. What started as a discussion to 'break bad news' can in fact become an opportunity to reassure. People look for explanations for illness, and in their absence will often assume that inheritance, upbringing and/or contagion might be a factor.
- **What they understand.** Even those who have had no prior experience will usually bring to the discussion some preconceptions which may be unhelpful and should be identified during the alignment phase. This is particularly true regarding the implication of the diagnosis and especially prognosis. Many families will assume a diagnosis of leukaemia is universally fatal, or at least always causes long-term damage, or that a bone marrow transplant (often thought to involve surgery like a solid-organ transplant) will be necessary.
- **What vocabulary they use.** It is during this listening phase that doctors should note how the family uses certain aspects of language, both by listening to the words that are used and those that are avoided. The term tumour, which to doctors can mean benign or malignant disease, is usually synonymous with 'cancer' to lay people. Some families studiously avoid using the term 'cancer' or 'leukaemia' preferring instead 'tumour of the blood'. If this is the phrase that the family already understands and which accommodates their coping mechanism, forcing them to use a more precise term may

jeopardise both their understanding and their coping. It is also discourteous; constant and unnecessary corrections emphasise the power imbalance between doctor and patient.

Tools available to the professional during this stage include:

- **Open questions:** These are questions that encourage someone to define the agenda of the discussion by allowing them free rein to decide how to interpret the question. There are different ways of doing this; a good one is to start by saying “We haven’t met before, so it would help me if you could summarise for me what has happened up until now”. This allows the family to interpret the question in whatever way they choose. Such an approach can often be dramatically revealing, such as the response “Well, it all started when we moved near some power cables after my husband left us four years ago”.
- **Closed questions:** Closed questions are often considered less helpful, as their object is to narrow down the discussion and focus on specific issues. Carelessly used, their effect can be to restrict discussions to what the doctor wants to talk about, rather than what the family needs to hear. Nevertheless, closed questions can be crucial: consider, for example, the importance of an answer to the question “has anyone in your family suffered from leukaemia”. Discussions with no closed questions can be poorly-focused and deeply unsatisfactory.
- **Summarising and checking:** Since the purpose of the alignment phase is to gain an understanding of the perspective of patient and family, it is important to confirm that our understanding is in fact accurate. This can be done, for example, using the formula “From what you have said, it seems that you already suspected/understand/worry about etc...” This is an opportunity for families to correct the doctor, or to confirm that his understanding is correct. Even if no correction is needed, it allows the family to feel the professional has listened to them, and the doctor to gain a better sense of their information needs.

### 3. Imparting information

Although, as has been seen, it is an important goal of discussions with families that they feel listened to, this is rarely enough. The doctor is expected to be able to give information in an authoritative way. Furthermore, it is important that information be received and understood accurately by the family, since competent collaboration is necessary in caring for the patient.

Information should be imparted at an **appropriate level** and an **appropriate pace**.

**Appropriate level:** The appropriate level is the information needed to deal with the immediate situation, and that necessary to allay the family’s major fears and anxieties. At

the time a diagnosis of leukaemia is made, for example, it is important that the family should understand the nature of leukaemia, the immediate tests that are required and the significance of their results. Families will commonly ask for information about increasingly remote possibilities, giving ever more speculative 'what if' questions. The result can be discussion of more and more complex and uncertain possibilities, the vast majority of which will never happen. Paradoxically, passing on too great a volume of information in this way will reduce exchange of the information that is really needed. Giving too much information can be as detrimental to communicating understanding as giving too little. There is a difficult balance to tread between appearing to avoid answering questions, and resisting the temptation to discuss in detail possibilities that are unlikely. Furthermore, families will usually expect from a doctor some indication of what his or her own opinion is. Often, questions raised by families at the initial interview will reveal more general concerns which may need to be addressed. For example, detailed questions about the side effects of chemotherapy before leukaemia has been confirmed, let alone classified, may indicate a concern that even if the child is cured, he or she will be left with long term damage. Whilst addressing the specific detail of different chemotherapy protocols may not be appropriate, reassurance that most cancer survivors are healthy certainly is.

It may be necessary to close down parts of the discussion that range too far into the speculative. In this situation, it can be helpful to make a further appointment at a specific date and time once further results are available. This avoids a sense of abrupt closure.

There is often surprisingly little difference in understanding of practical care between families between those of a high level of education and those without. What is often needed, however, is for the same concepts to be explained in different ways. The danger here is of sounding patronising on the one hand or incomprehensibly technical on the other. One way to minimise the risk of either extreme is to avoid using jargon words, using instead the terms chosen by the family themselves.

So, information should be given at a level that is appropriate for the needs of the family at that time. Most families will need more or less the same amount of information, irrespective of their educational level. It is therefore the doctor's responsibility to ensure that information is imparted in a way that is comprehensible to the specific family.

**Appropriate pace:** The rate at which people can assimilate information depends on a large number of uncertain factors. It includes their prior understanding, both because of their background and experience and also how much has already been discussed with them beforehand. There is no way to know how quickly a family is ready to receive information except by continually checking. A useful way of ensuring that information is being given at the appropriate rate is to use summaries. These serve to reiterate what has been said, to punctuate the discussion and provide a pause, and also a chance to invite questions. A typical summary would be something like:

'So we've talked about the two different sorts of leukaemia, lymphoid and myeloid, and the fact that they are treated quite differently and that lymphoid is on the whole easier to treat than myeloid. We've also talked about the fact that before we can know which it is, we will need to do a bone marrow and we talked a little bit about what that will involve and in

particular the fact that he will be asleep when it is done. Is there anything you would like to ask about those things before we go on?’

Written materials can be valuable adjuncts to communication. Drawings made during the discussion can often help to clarify what is being said, but if they are complex it is often a good idea to have practised them beforehand. Good quality written materials for families to take away can provide ongoing information that can be accessed at an appropriate pace and without pressure. However, written material alone has its limitations and should not usually be used without an opportunity for discussion with a knowledgeable person. It is difficult for any process of alignment to take place before printed materials are read, so that families may find themselves presented with a series of words that are unfamiliar but carry a message of dire news they are not yet prepared to hear. Poor written information may be positively harmful, but there are many printed resources of great quality and these should be made available to families after or at the time of the discussions.

Written materials also give an opportunity for families to access their own reference resources outside the meeting in order to clarify or expand on what has been written. The internet is, of course, a mixed blessing in facilitating the development of expertise among families. Much of what is published on the net is strongly held opinion rather than having a basis in fact. Nevertheless, there are also some extremely valuable resources. Families will access the internet anyway and if they are told they shouldn't, most will simply do so without letting the medical team know. The wisest approach is probably to encourage families to use the internet, but invite them to bring what they discover back for further discussion. It is also helpful to provide three or four reputable and relevant internet locations.

#### 4. Checking

It has already been seen that information should be imparted at a pace that is appropriate, and that the only way of knowing what is an appropriate rate is to check with the family that they are happy to move on to the next stage of discussion. This is equally true once all the information has been imparted. Again, the only way to know if the family feels they have had enough information (and feels their concerns have been addressed) is to ask them. The technique of summarising is useful at this point but even without that, the question should be asked: ‘Before we move on, is there anything you would like to ask about what we've already discussed?’ It may be helpful at this point to reassure families that they will not be thought stupid if they do ask a question: “no one expects you to remember everything first time and we are perfectly happy for you to ask again. If I am not here, my nursing colleagues are around and will usually be able to answer your questions.” Such an approach also empowers and supports your nursing colleagues as sources of expert information in their own right.

It can be tempting, especially if time is limited, to invite questions in a way that actively discourages them: "You haven't any questions, have you?" Generally, families will need positive encouragement to ask.

If checking reveals that some areas of the discussion have not been understood as well as you had thought, it will be necessary to go back over the information again. This may need to be done many times. Rarely it may be necessary to guillotine the discussion, for example if it becomes clear that the family is simply unable to take in the information at that time.

### 5. Future plans

It is important the family does not feel they are being abandoned at the end of the interview. Most families will feel reassured and more secure simply knowing that there are plans for further conversations. In the first instance, it is valuable to introduce other members of the team, ideally by having them to hand during the discussions, and to refer to them during the conversations so that families recognise yours is not the only expert voice. Assurances such as 'the nurses who work on this ward are very familiar with children with leukaemia and are always available to answer questions while you are on the ward' can be both encouraging for families and supportive for colleagues. It may be helpful to add that if they are not sure of the answer they will know whom else to ask; this allows colleagues to involve senior members of the team without feeling they have lost face in doing so.

For children who are to be discharged home, the contact may be the primary care team, or a nursing outreach team. It is helpful to provide a contact phone number if at all possible.

At the same time, families will often appreciate knowing that there will be a second opportunity to discuss things with the person who has initially given them the information. In an outpatient setting, this is achieved by arranging their next visit. On the ward, it is helpful to set a time and a day when the discussion can take place. It is important to remember that these appointments will be of enormous significance to families so should not be undertaken lightly. For example, if it is not possible to be sure of the exact time on a Tuesday when the next meeting should take place, it is better to say 'I will be there some time on Tuesday afternoon but can't say exactly when' rather than giving a spurious appointment time and then not being able to be there. Generally, families fully understand that doctors' lives are busy and often unpredictable and that they may not be able to give an exact time.

Finally, it is important to ensure that the plans that have been drawn up for meeting again are acceptable to the family. This of course particularly important if the child is to be discharged into the community since, if the plans are impractical for the family, the child will simply default and be lost to follow-up. So, once again, the conversation should finish by summarising what has been said and inviting questions.

## Summary

's role is essentially to ask the minimum number of questions necessary to illicit information from the family about their own fears, anxieties and understanding. This is followed by a period when the doctor gives information in a way that takes account of the way in which the family is most likely to be able to assimilate it accurately and easily. Before leaving this section, the doctor should ensure that what has been said has been understood. This can only be done by asking and, if necessary, by repeating the information. Finally, a plan of action should be evolved which should include arrangements for the discussion to be continued both on an ongoing basis (for example with the nurses on a specialist ward) or at a specific future discussion. This should allow the twin purposes of communication with families – the passage of information, and establishment of a sense of being 'valued' – to be achieved.

## Communication with colleagues

Colleagues, too, need to be treated with courtesy and respect. This is more than the simple dictates of etiquette; it is important because it is essential to good communication and therefore impacts directly on patient care. The result of brusqueness or rudeness is to irritate, and the result of irritation is usually to close the door to further discussion. Courtesy is important because it helps avoid positions becoming entrenched and instead encourages exchange of professional views.

For situations in which important patient data is to be passed on to colleagues, a combination of verbal and written communication is ideal. Verbal communication is the most effective means of exploring, explaining or clarifying a difficult clinical situation. A verbal handover, for example, allows information about patients to be passed on, but unlike a written handover it can also communicate less concrete aspects; something about relative urgency, non-specific worries, a condition that is improving or worsening, or other diagnostic possibilities that have been considered.

Written information, on the other hand, is particularly valuable when data needs to be stored in such a way that it can be easily accessed by different professionals on many occasions. Writing in the notes is usually done by a junior member of the team, and is often seen as something of a chore. As the only permanent record of most of the clinical decisions that are made by a team, it is imperative that entries in medical notes are written well. It is self-evident that written information should be accurate. Notes should be legible, dated and signed with a name that can be read, and some brief description of role (eg. paediatric SHO), ideally with a contact bleep or extension number. They should be structured, beginning with a brief summary of the problems existing and new (including important medications, eg "Ribavirin day 4"), of the history and examination findings, a brief summary of the status that day ("Generally better, but some respiratory problems remain, cause unclear, NPA awaited"), and a bullet-point list of plans arising out of that

day's assessment. This is sometimes known as the 'SOAP' system: Subjective (ie what others and the patient tell you) Objective (ie what you find on examination), Analysis (ie how you interpret the situation) and finally Plan.

In outpatients, the main record of an appointment is the letter to the GP. These are usually more easily legible than hospital notes as they are typed, and provide a valuable cumulative narrative over months, years or even decades. They are typically written by diverse doctors, of all seniority, many of whom will have moved on from the team at the time their letter is read. Again, the need for letters to be clearly and systematically written is obvious, and the SOAP system works well. Letters should, where possible, be kept to less than one side. The two most important elements of an outpatient letter are a problem list or introductory paragraph summarising the issues, and a closing paragraph detailing the plan. This should include further possibilities (eg "If tramadol is ineffective or poorly tolerated, we should consider introducing a small dose of morphine").

It is perhaps ironic that for paediatricians, the main role of a 'GP letter' is often seen to be to provide a record for other members of the paediatric team rather than for the GP. A letter written with this in mind may not be enough if you are asking the GP to become actively involved in the child's follow-up care in the community. GPs have to read a huge number of letters each day, more than they can possibly read, and are faced with the task of identifying from this deluge those that need them to take some action, rather than simply informing them that someone has been seen. Even where you are not asking the GP to undertake some specific task, it is the primary care team who will usually renew the prescriptions you have started. They are in the position of needing to write up medications you have prescribed, on patients they may not have seen for some time. If the child is to be managed safely by collaboration between hospital and primary care teams, the GP needs to have information presented in a way that is clear, accurate and quickly assimilated. You can readily derive a set of 'dos and don'ts' of writing to GPs simply by imagining yourself in the position of the GP who has to read the letter.

#### *1. Do ask the patient which GP to write to.*

Until recently, every patient was registered with a single GP, but nowadays, patients are registered with a practice, and before long there will be the option to be registered with two or more practices. Most hospital computer systems, however, currently automatically insert into a letter the name of the registered GP and this is unlikely to change in the near future. Despite changes in GP cover, most patients will continue to have a preferred or 'usual' Dr, and it is to this individual that the letter should ideally be addressed. The easiest way to ensure this might be to ask the patient or parent, or to reply to the GP who referred the patient. A GP tends to read more thoroughly a letter bearing his or her name. The same applies to addressing the letter to the current registering practice.

#### *2. Do begin the letter with a statement of the diagnosis.*

Where available, a diagnosis (or diagnoses) should be stated at the beginning of the letter. GP notes are usually computer-based and use a diagnostic code for diseases, such as the

Read code. Where there is a locally agreed disease coding system, including the relevant code in the GP/clinic letter is helpful, particularly for new diagnoses.

### *3. Do keep it short and well organised.*

The shorter a letter is, the more likely that a GP will read it thoroughly. Arguably there is a conflict here between the two roles of the clinic letter – a record for hospital notes on the one hand and communication with the GP on the other. A particular bug-bear for GPs is having the contents of their own referral letter regurgitated in a clinic letter, yet these details do need to be recorded among the outpatient letters. In fact, however, even for the record this is really only necessary on the first visit. Reiteration on subsequent occasions is unnecessary and results in a letter that is turgid and difficult to read - for primary care and hospital teams alike. To enable GPs easily to skip what they already know, one solution is to preface this paragraph with “to summarise the background” and/or to use subheadings (eg ‘GP Action’) to draw attention to the relevant sections of the letter.

### *4. Do not use specialty-specific jargon.*

Another barrier for those trying to assimilate the information in clinic letters is the use of terminology or abbreviations seldom used outside the specialty. GPs should not be expected to need a dictionary of paediatrics to translate your letter. Courtesy, as well as the interests of effective communication, demands that you use a professional vocabulary you have in common. Even among paediatricians, some abbreviations can be highly ambiguous: a patient who needs a ‘PEG’ may end up with a gastrostomy, laxatives or a form of asparaginase chemotherapy.

### *5. Do write a management plan.*

Management plans facilitate an effective and efficient collaboration between professionals, both between primary and hospital teams and within them. It is not always easy to see why a certain paediatrician at a certain time chose a particular course of action, nor what second and third options were considered. A management plan along the lines of “if X fails, I would recommend Y or Z” allows others to see what your long-term strategy is. It also allows the primary care team to continue your management plan without the child needing to wait until the next visit to you or, more likely, someone else on the paediatric team.

This should include a clear plan for follow-up, whether your plan is for that to be in primary or secondary care. The time-honoured closing formula “we would be happy to see him again.....” emphasises that you have discharged the patient, but can be irritating to read, as willingness to review the child should go without saying. If the phrase is necessary, it can perhaps be softened by adding “of course” to indicate that you acknowledge this.

### *6. Do give clear, consistent and constructive messages to the family*

Where a specific ‘GP Action’ is recommended, it is helpful to spell out what has been said to the patient. If a GP reads that he or she should be altering medication, this will be translated into a change on the patient’s prescription list. The GP needs to know whether

the patient/parent has been told the prescription will be ready, or whether they are expecting the GP to call first to let them know it is ready, or whether the prescription is contingent on follow up investigations/examinations etc. Care of the child is through collaboration with the primary care team, and it is important that their working relationship with the family is not jeopardised by unclear or undermining messages from the hospital.

In this regard, it is also helpful to remember that it is rarely appropriate to collude with families who castigate their GP. Apart from anything else, families with this habit will probably be representing the hospital team in parallel discussions in a similarly critical light to the GP. It often appears that some agreement is required with the observation “I kept telling them that there was something wrong but they wouldn’t listen”. The need for families is usually for their anger to be acknowledged and understood, rather than encouraged and fuelled. Paradoxically, indeed, most feel more anxious and uncertain if professionals allow themselves the luxury of uninformed criticism of one another. Rather than joining in the heaping of coals on the head of an unfortunate and absent GP, a more appropriate and effective response from a paediatrician is to acknowledge the importance of the issue with an empathic “That must have been frustrating” or even “I can see that made you angry”. Such an acknowledgement is true, helpful and supportive irrespective of the actual circumstances, but does not imply that you agree that the GP (to whose care they will soon return) is incompetent. Having expressed their anger and seen that it is understood, families will often not feel the need to mention it again and the collaborative relationship between family and professionals in primary care and hospital teams is unscathed.

If, in your view, there are real grounds for concern about the way in which a GP has acted, the best solution is to take it up in discussion with senior colleagues. Again, as a matter of courtesy, it is rarely appropriate for junior members of the paediatric team to take it on themselves to contact a GP with a view to correcting their practice. ‘Educating’ GPs is a delicate matter: some are grateful and some offended. Most do, however, rely on specialists to disseminate knowledge and best practice, so if the referral illustrates a learning need the issue should not be ducked.

#### *8. Do draw attention to changes in prescription*

Any change in medication should be typed in bold type, listed before the body of the letter, or as a last resort highlighted by hand at the time the letter is signed. An exhaustive and up-to-date medication list is useful, but can be misleading unless it is strictly accurate. Patients may be under several different consultants, so that your knowledge of their medication list may be incomplete. Remember that after the first month of a hospital prescription, what the patient will actually be prescribed, and will therefore be able to take, depends upon what is entered onto the GP computer.

#### *9. Don’t always wait for the letter to get through the mail.*

Realistically, even if you dictate a clinic letter the moment you have seen the patient (as is ideal), there will usually be a delay of around a week while it is typed, signed, posted and finally received and read. If there is any likelihood that the GP may need to know the

outcome of the clinic appointment this period, it is better to fax it, or better still, to contact the GP by telephone. Many GPs do visits during the afternoon, and may be easier to contact during the morning. Receptionists have a reputation for being highly skilled in protecting GPs' time by deflecting calls. This reputation is perhaps unfair; it is established as a result of the need to avoid interrupting consultations for a GP to speak to patients. There is no dedicated doctors' hotline. In reality, most receptionists will quickly recognise the need to put another doctor through immediately. A useful phrase is "I need to speak directly to Dr X about a patient of ours". It is helpful to state at the outset whether the urgency is such that the GP should be interrupted during a consultation. If the GP is out on visits, ask for a mobile 'phone number. Messages are less satisfactory: you will have no way of knowing whether or not it has got to its recipient. If you have the address, email is the obvious solution, but is still beset by fears about confidentiality.

## Summary

Like patients, professional colleagues are part of a collegiate relationship which, in order to function smoothly, demands communication that is sensitive and affirming. Again, we have suggested some practical ways in which this can be achieved, but underlying all these suggestions is the principle that people should feel they are valued as part of a team supporting and caring for the child. Information exchange should of course be accurate, but accuracy alone is not enough. It needs to be made accessible and easily assimilated. Whilst this can be challenging, particularly when communicating with colleagues outside the hospital, it is an essential part of clinical care. It is not simply an issue of politeness, or professional courtesy and etiquette: children's safety depends on it.

## Goals of communication

To enable the family of a child or young person to become competent colleagues in his/her medical care through:

- Imparting factual information and understanding:
  - to an appropriate level
  - at an appropriate pace
  - using appropriate language
- Imparting a sense of participation in the team through:
  - Seeking their perspective
  - Empathic acknowledgement (implied and overt) of their concerns
  - Soliciting their views in decision-making.

	Goal	Tools
1. Setting the scene	<p>To remove barriers to exchange of information by:</p> <ul style="list-style-type: none"> <li>• Creating physical space</li> <li>• Creating temporal space</li> <li>• Using appropriate body language</li> <li>• Including appropriate people</li> </ul>	<p><b>Arrangement of room</b></p> <p><b>Handing over bleep</b></p> <p><b>Eye contact</b></p> <p><b>Inviting spouse and others in family</b></p>
2. Alignment	<p>To seek perspective of family:</p> <ul style="list-style-type: none"> <li>• What have they already been told, and <i>what does it mean to them</i> (eg does leukaemia mean to them they will inevitably lose their child) ?</li> <li>• Have they any prior experience and/or (mis)conceptions ?</li> <li>• What vocabulary does the family use, and what words do they strenuously avoid ?</li> </ul>	<p><b>Open questions</b> – to allow family to set agenda and broaden the discussion to identify new areas that need to be addressed.</p> <p><b>Closed questions</b> – to obtain specific, often detailed, information about certain areas.</p> <p><b>Summarising and checking</b> – serves at least four functions:</p> <ul style="list-style-type: none"> <li>• Ensures the family's understanding is accurate.</li> <li>• Ensures the doctor's understanding of what the family understands is accurate.</li> <li>• Allows the family to feel their competent involvement is given high priority by staff.</li> <li>• Allows one section of the discussion to be rounded off and another begun.</li> </ul>
3. Imparting information	<p>To give information to family:</p> <ul style="list-style-type: none"> <li>• At an appropriate level (neither confusingly complex nor patronisingly simple)</li> <li>• At an appropriate pace</li> <li>• Using appropriate language</li> </ul>	<p><b>Drawings and diagrams</b> – can be helpful in clarifying complex issues, particularly if done as doctor speaks. A good idea to rehearse these beforehand.</p> <p><b>Printed materials</b> – many available, often local. Internet most obvious and most widely accessed. Printed materials:</p> <ul style="list-style-type: none"> <li>• Can be accessed repeatedly and in family's own time</li> <li>• Allow external references to be made (eg to web-based resources)</li> <li>• Are generic and may apply only incompletely to the individual patient.</li> </ul> <p><b>Summarising and checking</b></p>
4. Checking	<p>To establish that :</p> <ul style="list-style-type: none"> <li>• information has been accurately received <i>and understood</i></li> <li>• no new questions have arisen that should be addressed</li> <li>• the pace of discussion is appropriate and it is acceptable to begin to close the discussion</li> </ul>	<p><b>Repetitions</b> as often as necessary</p> <p><b>Reassure</b> that everyone needs things to be repeated</p> <p><b>Actively solicit questions</b></p> <p>Explain that there will be <b>other opportunities to ask.</b></p>

		Rarely, need to 'guillotine' discussion
5. Plans	<p>To ensure family feels 'safe' having been given the information:</p> <ul style="list-style-type: none"> <li>• Knowing there will be another opportunity to ask questions of the interviewer</li> <li>• Knowing there are other accessible expert people who can answer questions in the meantime</li> <li>• Having a clear idea of what the next steps are and what depends on their outcome</li> </ul>	<p><b>Numbering</b> steps on fingers</p> <p><b>Checking</b> plans are:</p> <ul style="list-style-type: none"> <li>• Understood accurately</li> <li>• Acceptable</li> </ul> <p><b>Drawing attention</b> to other sources of information:</p> <ul style="list-style-type: none"> <li>• Ward staff</li> <li>• Specialist nurses</li> <li>• Other medical colleagues</li> <li>• Internet sites</li> <li>• Printed materials</li> </ul>

## Communication Skills Tools

*Tim Warlow*

One of the great challenges in understanding the goals and wishes of children and families and providing them much needed information towards the end life, is ensuring clear two-way communication. Many of these conversations are in one sense or another 'breaking bad news'. Whether the child's condition changes or the approach to managing the child does, many of the steps towards the end of life involves loss to that child and family. As health professionals we need to understand what children and families know already, impart information sensitively and ensure understanding and ongoing support. Many of us do this naturally many times a day in our practice. However, when conversations relate to death and dying we can avoid discussing the topic or withhold difficult news. Our own sense of inadequacy, lack of training, insufficient time and fear of negative impact on the child or family all contribute. It is at these times that having a strategy for communication can help to support quality communication and facilitate the goals, wishes, fears and hopes of the family being heard. These goals and wishes can then become the cornerstone of our family centred advanced care planning.

Two of the many tools which can help in such situations are the 'Cardiff Toolkit' (Pearce and Finlay 2007) developed here in Wales, and the 'SPIKES protocol' (Baile and Buckman 2000). Both are taught on the 'Palliative Medicine for Health Care Professionals' MSc hosted by Cardiff University. These tools are outlined below and will provide a framework for practice scenarios used in the 'Handling Difficult News in Paediatrics' workshops.

### The Cardiff six-point toolkit

The Cardiff Toolkit breaks down key aspects of any palliative consultation, offering tools which can be refined by professionals. It supports open conversation as well as the use of 'breaking bad news' communication protocols such as SPIKES. The six points are not in any particular order but all require consideration at various points throughout the consultation.

The six points are:

- Comfort
- Question style
- Language
- Listening/use of silence
- Reflection/acknowledgement

- Summarising

### 1. Comfort:

Ensuring all parties are comfortable physically and feel safe emotionally is vital when having difficult discussions. Consider the following:

- Setting: Appropriate room, quiet, no interruptions, lighting.
- Physical comfort: Seating, positioning of those involved.
- Emotional comfort and ease: Tone of voice, greeting, courtesy, allowing and encouraging the expression of emotion, avoiding the temptation to provide false reassurance or false hope.

### 2. Question style:

Employ a variety of question styles to fully explore goals, wishes, values, fears and preferences of the family, encouraging discussion of difficult topics where information needs to be shared. Avoid asking multiple questions in the same sentence or leading questions directing the patient towards the answer you are seeking.

- Using open questions to illicit complete information in patient's own words e.g. 'How have things been?'
- Focused questions to explore topics raised during open questioning or challenge e.g. 'Tell me more about your pain?'
- Hypothetical questions to explore possibilities or probabilities in relation to difficult issues e.g. 'Have you ever thought about what might happen if the chemotherapy does not work as we hope?'
- Direct questions to clarify key points e.g. 'Do you feel any numbness or tingling?'

### 3. Language:

Up to 60% of communication is non-verbal, 33% the tone of voice we use and 7% the spoken word. Language considers all these aspects.

- Consider body posture, expression and overall demeanour to communicate concern/compassion. Appropriate eye contact is vital.
- Consider tone of voice and pace of speech (eg slow, calm speech when managing angry reactions or denial).
- Avoid jargon, use simple developmentally appropriate words the patient can understand.

### 4. Listening/Use of silence:

Silence helps by allowing the patient to assimilate news, ask a question or react to difficult news. It can be harder for the professional than the patient to be silent at key points but it is vital to enable bad news to be digested and reactions explored.

- Allow the patient to talk – avoid interrupting until the patient has told the whole story.
- Encourage continuation of dialogue with words such as ‘yes’, ‘I see’, or maintaining eye contact and using appropriate body language.
- Once difficult news is shared, allow silence until broken by the patient themselves, either verbally or by a change in posture/gesture.

### 5. Reflection/Acknowledge:

One of the most powerful tools is using short phrases to reflect back what has been said encouraging further disclosure:

*Father: ‘Life is going to be very difficult from now on.’*

*Doctor: ‘Difficult?’*

*Father: ‘I don’t know how my wife will cope when Jacob gets more unwell.....’*

Reflection demonstrates that you are listening. It encourages the patient to continue their story or clarify what the concern or issue is really is about. Equally, a question can be used to reflect back to the patient to encourage further dialogue. This is especially useful when patients make comments to which there is no straight forward answer, or where a deeper concern underlies a more general question:

*Teenager: ‘Doctor, I’ve been thinking for a while....am I going to die?’*

*Doctor: That is a very difficult thing for you to have to think about, what makes you ask that now?*

*Teenager: ‘I need to make sure my girlfriend is ok without me.’*

This process of reflection, as well as genuine sympathy and good non-verbal communication ensures the patient feels acknowledged in their concerns. This builds trust and opens the door for more difficult conversations which the health professional may have to initiate.

### 6. Summarizing:

Summarising is the process of taking salient information given by the patient and recapping this back during the consultation. It demonstrates you have been listening, allows the clinician to clarify points made, provides opportunity for the patient to add further points or details, and provides a way of re-orientating the consultation if it has lost direction. Summarising and reflection are both useful tools if as a clinician you get stuck at any point in the consultation and need to regroup before continuing the discussion.

## SPIKES – A six step protocol for delivering bad news

Effective communication of difficult news is vital to avoid misunderstandings and enable patients and families to plan effectively for the future. It ensures patients concerns and fears can be addressed, as well as their expectations of treatment in the future. It can be extremely stressful, especially where the possibilities for further life sustaining treatment are limited, or if the news is not expected by the patient and family. Many studies have demonstrated that families do want more information, and greatly value being told the truth even if it is not what they want to hear. Significant harm and future regret can result if false hope is given or facts omitted, as families are robbed of their ability to make decisions or plans based on the reality of their situation.

Key goals in breaking bad news discussions include:

- Gathering information from the patient to determine current knowledge, expectations and preferences for amount and type of information they wish to receive.
- Provide the right amount of intelligible information in line with the patient's wishes.
- Support the patient in receiving the information
- Provide an ongoing plan jointly.

The six-point protocol below provides a suggested outline for achieving the goals above. There is much overlap with the Cardiff Toolkit, and many parts of the toolkit can be incorporated into the steps of this protocol.

### ***S - Setting up the interview***

Privacy, ensuring all relevant people are present, ensuring no interruptions and adequate time for discussion. See Cardiff Toolkit 'Comfort' section.

### ***P – Perception: 'What do you already know?'***

Ask before you tell. Use open ended questions to understand what the patient or family know about the condition, thoughts they have had concerning the news to be shared. This is vital if information shared is to meet the patient's needs and be properly understood.

### ***I – Invitation: 'What do you want to know?'***

Whilst most patients and families wish to know full details about the news to be shared, some do not. It is prudent to ask how much information patients wish to know, and what sort of details are important for them. Some patients prefer statistics and percentages, others a drawn diagram of the condition.

### ***K – Knowledge: Warning shot then breaking the news***

- Warning the patient bad news is coming can lessen the shock e.g. 'Unfortunately, the news is not what we had hoped.....'
- Use simple, clear language with no jargon. Ideally use words and phrases used by the patient in relation to their own condition. Avoid bluntness or harshness.
- Give the information in chunks and check for understanding.
- Remember, if there are no life sustaining treatment options, care and treatment still continue but the goal of that treatment changes. There is never a time when 'there is nothing more we can do.'

### **E – Empathy**

- Leave time for the patient to respond before providing more information.
- Observe the emotion of the patient – silence, anger, denial, grief, shock.
- Identify the emotion observed
- Acknowledge the emotion then explore this with the patient if appropriate e.g. 'I can see this is very upsetting for you to hear', 'You look very worried, what particularly are you worried about?'
- Validate the patient's response e.g. 'It is completely understandable that you feel this way.' 'This is a very normal reaction.'

### **S – Strategy and Summarise**

The initial consultation may not be the right time to discuss an ongoing plan but for some it reduces anxiety and uncertainty and reassures that support will continue. Explore the patient's wishes and goals moving forward. Summarising the discussion provides opportunity to ensure understanding and clarify points discussed.

There are many other strategies for breaking bad news and some professionals find no strategy is needed at all. The principles of the Cardiff Toolkit and SPIKES protocol can be modified and incorporated into your own communication repertoire and used to reflect on your own communication skills in real life scenarios.

#### **References:**

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Baile et al. Spikes – A Six-step protocol for delivering bad news: Application to the patient with cancer. The Oncologist. 2000;5:302-311

## Section 2: Advance and emergency care planning

### Introduction

*Richard Hain*

If you were to ask those working with children what they mean by 'Advance and Emergency Care Planning', you would probably get lots of different answers. For some, it is simply another name for the DNACPR order (Do Not Attempt CardioPulmonary Resuscitation). For others, it is a record of the instructions that parents give for what doctors should do if their child becomes acutely and severely unwell. For others, the purpose of an Advance or Emergency Care Plan is primarily that it indicates a child should no longer be admitted to the intensive care unit if they become seriously unwell, because they are now seen to be 'palliative'.

Although there are elements of truth in all of those, none of them is entirely correct. The main function of advance and emergency care planning is to facilitate dialogue between the child's family on the one hand, and health care team on the other, about what might and should happen as a child's death seems to be approaching. That is important, because without such a dialogue it is easy to fall into one of two errors about the relationship between what the family wants, and what the healthcare team should offer. It can be tempting to imagine that the parents' view is irrelevant, and that it is doctors who should make that decision, solely on the basis of what, as a matter of medical and scientific logic, is best for the child. On the other hand, it may seem to some that decisions at the end of life are entirely those of the parents.

### Who speaks for the child ?

There is no doubt that most children, especially those with life-limiting conditions, do need an adult to speak for them. Most are non-verbal, either because they are too young to articulate abstract concepts or because they are cognitively impaired. The job of an adult speaking for a child is to express what the child's interests are. But there are two different sorts of interest. The first sort of interest (objective interests, or needs) are the sort that do not depend on the individual child herself. They are simply facts about the universe. That would include, for example, a child's need for oxygen or for food. Those needs are not subject to anybody's opinion or experience; we can know them simply by knowing enough medicine and some facts about the child that we can observe and measure. Those objective interests need to be articulated by someone who knows the facts, and that is most likely to be a doctor.

But there are also other interests that depend on the nature of the individual child. Those can be called subjective interests, or preferences. Some children prefer to take their medicine as tablets, while others prefer syrup. For most children, there is no rational reason why one should be better than the other. It is simply a matter of what that individual child prefers. These subjective interests must be expressed by someone who knows that individual child well. Ideally, it would be the child herself, but if the child cannot express what she wants, it needs to be the person who knows her best. For most children, that is her parents. What that means is that where parents need to make decisions on behalf of their children, they must make it on the basis of a correct understanding of what the child's needs are, and an ability and willingness to articulate the child's preferences rather than their own.

So one reason why it is important for the health care team to take seriously what parents want is that parents are the people most likely to know the child, and what the child might prefer. Another is that parents are colleagues. They are the people on whom the impact of any decision about the childcare at the end of life will be the greatest. A third, more controversial, reason is that to a certain extent the well-being of parents is the responsibility of the paediatric team. There is no doubt that it is the child who is our first and major concern. It can even be part of our responsibility to oppose the wishes of parents where they are for something that would, as a matter of fact, harm their child. At the same time, the interest of most children cannot be entirely isolated from the well-being of parents. Children are likely to be better cared-for by parents who feel confident and well supported than those who feel undermined and kept in the dark. And in any case it is a matter of human compassion that we also concern ourselves with what is best for the child's parents. It is correct for paediatric teams to say that the needs of the child must carry more weight than the needs of the parents, but that is not the same as saying that the needs of parents have no weight at all.

The purpose of advanced planning is not only to record what parents want doctors to do, or to set out what the doctors are prepared to do. Rather, it is a dialogue in which health care team and parents bring their respective expertise to bear on an exploration of what is, as a matter of fact, the best thing to do for the individual child.

### **The problem: different agendas, different timescales**

When it comes to decisions about medical intervention at the end of life, the sort of questions parents are asking themselves are often quite different in kind from those that health care team are considering. As well as wanting to know facts, parents are asking themselves questions that can have no clear answers: "What if he could have survived this episode? How do I know if he's suffering? What would God say if I let him die? What about my other children? Can I bear him to die at home? Should I expect a miracle? What if I agreed to let him die today and a cure were found tomorrow? How can I bear to know I'd seen his last smile?" And, perhaps

most difficult of all: “How could I live with myself if I agreed to stop?”

The question to health care team needs to ask, on the other hand, is quite simple: “Do we intubate him now or not?”. The decision needs to be made urgently, and primarily on the basis of physiological data available to the clinician in that moment. The questions being asked by the family need much more time. Many of them are ultimately unanswerable, others are not answerable on the basis of data alone but rely on perceptions and value judgements. All need careful exploration, consideration and reflection in repeated discussions over the course of weeks or months. It takes time – sometimes a lot of time.

There is therefore a problem. At the end of life, there is enough data for the medical team to make a decision, but there is no time for the family to think through their existential questions. But in order for there to be time to the family to work through their own questions, advanced planning has to be commenced many months before death is expected. At that point, there is not enough information to be clear what the mode of the child's death will be. If end of life planning is left until the end of life, there is data but there is no time. If it is introduced much earlier, there is time but not enough data.

## What the PAC-Plan is

The purpose of the PAC-Plan is to support timely and sensitively paced conversations that resolve the conflict between the family's need for time and the clinicians' need for information. The PAC-Plan provides three things:

1. A 'script' that offers clinicians a structure for difficult discussions about end of life care.
2. A record of what has been discussed.
3. A means of disseminating the results of those discussions.

### 1. PAC-Plan as a script

The PAC-Plan explores three potential scenarios that might unfold at the end of the child's life:

- **An acute deterioration that is easily reversible.** An example might be if the child receives an inadvertent overdose of a respiratory suppressant drug. Under those circumstances, it is usually fairly obvious that a child should be intubated and ventilated while the effects of the drug dissipate, irrespective of the fact that she has a life limiting condition.
- **An acute deterioration that is irreversible.** Parents might need to consider what would happen, for example, if they went into their child's bedroom one

morning and found that she had died during the night. Again, it is usually clear that under those circumstances it would not be appropriate to make any attempt at resuscitation.

- **An acute deterioration that is potentially reversible, but only by interventions that are too harmful.** The more difficult scenario is where an intervention might potentially reverse an immediate deterioration, but that the cost to the child (in terms of the harm it would cause her) would be too great to justify introducing it. Most parents understand that idea, but need time to consider its implications for their own child. It requires parents to weigh the extension of their child's life (albeit only by a few months) against the distress and pain that resuscitation and ventilation will undoubtedly cause. For many parents, that is new information. It takes time to process the full implications.

## **2. PAC-Plan as a record**

The PAC-Plan provides a record of the content of, and agreements to, those discussions. It records that the discussion has happened, and some of the content (for example, the parent's preference for the place of care at the end of their child's life). It also sets out what the family would ideally like to happen in each of the three scenarios of deterioration: reversible, irreversible or potentially reversible.

It is important to make clear to families that the PAC-Plan does not constitute any kind of legal consent form.<sup>1</sup> Doctors do not need parents' consent to withhold interventions they consider to be, on balance, harmful to the child. The PAC-Plan is a record of what that what the family would ideally prefer, and it is reasonable to promise that the result of completing it will be to make it more likely that those preferences will be realised. But parents also need to know that it is not any kind of advance directive and is not legally binding on anyone.

## **3. PAC-Plan as a means of disseminating information**

The PAC-Plan is a means of sharing in a timely fashion the information that has been gathered, so that it can influence decisions at the end of life that might need to be taken quickly. It is also an opportunity to ensure that everyone who needs to know that the child is expected to die has that information on record, where it can be easily accessed at the time important decisions need to be made. That would

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<sup>1</sup> That is not as clear as it might seem. Parents do need to give consent for the information contained within the PAC-Plan to be disseminated, because it contains confidential medical data. They are also encouraged to sign the PAC-Plan alongside the signature of the responsible clinician, because it makes clear that both are comfortable that the record of discussions is accurate. But the PAC-Plan is not a consent form nor any kind of legally-binding advance directive.

include, for example, the ambulance service who need to decide whether to attempt to resuscitate a child in the home before transferring to the Emergency Unit, or to transfer straight to a children's hospice for end of life care.

The original version of the completed PAC-Plan is kept by the parents. That is important, because they need to know that what is written there is under their control. If a parent has a PAC-Plan that says the child should not be resuscitated, and chooses not to show it to the ambulance team, it says something about their own decision-making in that moment. Copies of the PAC-Plan should be in every version of the child's medical notes, including those in the Children's Hospital and the local paediatric unit as well as the GP. Relevant sections of the PAC-Plan are also disseminated to the ambulance service and to the police.

### What the PAC-Plan is not

The PAC-Plan provides a **script** for discussing end of life scenarios that are reversible, those that are irreversible, and those that are intolerable. It provides a **record** of the fact of the discussions, the place of care and/or death that the family would prefer, and the interventions they would ideally like to happen at the time of acute deterioration. Finally, it offers a **way of disseminating** the results of those discussions to the medical notes, the ambulance service and the police.

There are some important things that the PAC-Plan is *not*:

- It is not a new version of the DNACPR. It is no longer ever appropriate for the healthcare team unilaterally to decide that a child should not receive certain interventions on the basis of their illness.
- It is not parental permission to withhold some treatments. The medical team does not require such permission and parents on their own would not be in a position to give it.
- It is not a legally binding instruction by parents as to what the healthcare team should or should not do in the event of an acute deterioration. Parents do not have a moral or legal right to harm their child, and they do not acquire such a right simply by asking the doctor to do the harm for them. Parents should expect to be able to choose from among several reasonable treatment options to their child, but that does not extend to the right to choose an intervention that is not reasonable because it will, on balance, harm the child.
- It is not a pass that means the child should automatically be excluded from the intensive care unit. The presence of the PAC-Plan represents an acknowledgement by parents and health care team that the child's lifespan is likely to be limited. That is relevant to the discussion about whether intensive care is appropriate, but it does not render that discussion superfluous. Intubation and ventilation will certainly be justified in many children with life-limiting conditions who have a PAC-Plan in place. There

still need to be discussions with the intensive care team at the time they are considered.

## Summary

PAC-Planning assures parents that the healthcare team's goal, like theirs, is to do the best for their child. It assures them that their knowledge and views are important in achieving that goal, but that they will not have to make end of life decisions alone.

Parents cannot refuse treatment that is in their child's interests, nor can they insist on treatment that is not. Their views are nevertheless extremely important. Those views are complex, and need time to explore. The purpose of advance care planning using the PAC-Plan documentation is to provide a script to support those explorations, a record that they have taken place and what was discussed, and a means of disseminating the information to the people who need to know.

## **PAC-Plan in practice**

*Kath MacSorley*

When starting Paediatric Advanced Care planning with a family be prepared that these discussions may take an hour but more often take days to months of discussion and will develop and change over time and as the child's condition changes. The discussions are often challenging for the professional and families alike and are often very difficult for a family to undertake as they think about things that they would rather not think about. Some people are real planners and want to plan everything down to the last detail whilst for other families it will be enough to think about basic things as laid out in the PAC plan.

### **Who should complete the PAC plan?**

Any professional working with the family can complete or contribute to the PAC planning process – It does not have to be the Palliative care team (although they are always happy to help and advice with and support the process). It is best done by a professional who knows the child and family well and is available to support them through the process. However one of the child's consultants should be involved at some point. This professional will have a feeling for the best time to introduce the PAC plan and will know when it is and isn't a good time to talk with the family. Often you will go into an appointment with the intention of talking about the PAC plan but will arrive and know that this isn't a good time and at other times it may come up when you are talking about something else.

### **When to complete a PAC plan.**

If you would not be surprised if a child were to die prematurely, during this episode of care or within the next year it is probably a good idea to start thinking about a PAC plan. Often families will have heard about PAC planning from other families or professionals or it might come up naturally in conversation whilst discussing other things with the family. Sometimes especially if you know the family well you will already have some idea of what their wishes may be and what their fears are.

The best time to complete a PAC plan (although not always practical) is when a child is well and the family can consider things objectively knowing that they have time to think about things. Often you find a PAC plan will be discussed after a period of acute illness if the child has been very unwell and especially if they have been in intensive care.

### **Starting the process.**

Usually after deciding that a PAC plan will be completed a copy will be left with the family to look at. It is important that you explain that they do not have to fill this out themselves (this can cause a lot of stress for a family if they think you are leaving it for them to fill in) they can make notes on the copy if they wish but you will go back to them to discuss it and answer any questions they may have. You may at this point talk about who they would like

involved in the discussions and which consultant (if it is not the consultant leading the conversations) they would like involved.

It may be appropriate to discuss some of the information given in the previous section at this point – such as it not being a legal document and a document that will evolve and change with time and importantly that the family are not wholly responsible for decisions made at end of life but will be advised by and work in partnership with the medical team or this might be best left for future discussions.

### **Further discussions.**

Over the following weeks or months discussions may take place once or several times with health care professionals and issues discussed and information given. It is useful as a professional to think about the possible ways that the child may die – for example it might be because of deterioration in their disease or because of recurrent chest infections or gut failure many families will want to explore this and helping them to understand how this might happen will help them to make appropriate choices and decisions. Some families will have had experience of resuscitation and the paediatric intensive care unit and will probably need less explanation around these situations than a family who has not, but it is always good to discuss this – for example commonly parents who have seen an intraosseous needle inserted may not want their child to go through this experience again – but it would be important for them to understand the consequences of this.

During the process it might be necessary to involve other professionals such as the organ donation nurses – this might simply be a phone call to them to obtain information or it might mean them talking with the family.

Discussion about who the family would like contacted in an emergency or to support them if their child should die is also important, often we would recommend this is the children's hospice as they have family support teams that are on call twenty four hours a day and can support the family if this is needed.

### **Who to share the document with.**

Once everyone is happy with the document it is important to discuss who it will be shared with and gain the parents consent to share it with other professionals and outside agencies for example the police. When thinking about this it is helpful to think about whom else is responsible for the child at different times for example are they cared for by a respite team, do they go to school/nursery? Which hospitals do they access as well as health care professionals who are involved in their care.

At the moment Ty Hafan children's Hospice acts as a central repository for the PAC plans (this might change in the future) but we recommend that all the PAC plans are collated here so that if one can't be found anywhere else in an emergency a copy can be found there.

A copy of the form should be sent to the Welsh Ambulance service with the parents permission and they will place a marker on the house, so that when a call goes out from the home the crew attending will know there is a child in the home with a PAC plan and will

ask for it on entering the home. Page 7 of the PAC plan should be printed in a different colour to the rest of the plan so the ambulance crew can turn straight to it and know what management has been discussed.

Different police forces require different information, for example the South Wales Police don't require the PAC plan itself but just a form filling in (which can be obtained from the Palliative Care Office) whereas the Gwent police force have the whole document. (I need to check this with Pat – she isn't back until the 10<sup>th</sup>). The South Wales force use Dates of Birth on all their databases so they will need the parents dates of Birth. Again once the police have all the information they will place a marker on the house so if any calls are made to them they will know there is a child in the home with a PAC plan. It is important to let the family know that although involvement with the police is less likely if the child has a PAC plan they may sometimes still attend.

Obviously if there is a change in address or the child dies it is important to let the relevant agencies know.

A copy should also be placed in the front of the medical notes and on the relevant Trusts electronic records if possible. The original copy should stay with the family.

### **Additional documentation.**

Additional documents can be attached to the PAC plan; these may include symptom control plans, wishes documents, organ transplant wishes or emergency epilepsy plans.

The document should be reviewed regularly – this may be as the child's condition changes or yearly. It should be remembered that it is often traumatic for the family to have these discussions in the first place and so to review it will also be difficult for lots of families and will need to be done sensitively. Families often wish to change their PAC plan especially if the child becomes very unwell and they decide they no longer want unnecessary hospital visits or admissions to Intensive care.

If you are completing a PAC plan and need help or support the Paediatric Palliative care team in your area will be very pleased to advise and support.

## The PAC-Plan document itself



# Paediatric Advance Care Plan (PAC-Plan)



All-Wales

## Paediatric Palliative Care Network

*"Emergency care planning with families of children with life-limiting conditions is possible months or years before the end of life. Advance decisions evolve over time through the development of a trusting relationship and an ethos of shared decision-making."*

*Arch Dis Child 2010;95:79-82 doi:10.1136/adc.2009.160051*

Name: .....

Date of Birth: .....

NHS number: .....

Date of this review: .....

### PLEASE NOTE:

- This document is not legally binding. It is a record of discussions about preferences for what happens in the event of a child becoming seriously unwell.
- For it to be effective, relevant portions must be easily identifiable by ambulance staff in an emergency. The edges of Section 4 are printed in grey. Please also print a second copy of those pages on coloured paper and save it at the back of this document for ease of access.

**Paediatric Advance Care Plan (PAC-Plan)**  
Version 2.3

Name:  
NHS no:  
DOB:  
Address:

**Section 1: Frequently asked questions**

*1.1. What is this document for ?*

PAC-Plan is a tool for discussing and communicating the wishes of a child, young person and/or their family. Its main aim is to explore the various things that might happen as a child's illness progresses (particularly towards the end of life), but at a point when there is plenty of time to discuss them. The PAC-Plan has three functions:

- i. It offers the child or family an opportunity to explore what might happen in the event of a deterioration. Some causes of deterioration can be halted or even reversed, but others cannot, or could only be reversed by treatments that would be too unpleasant to bear.
- ii. It records that those discussions have taken place.
- iii. It documents what the child and/or family has expressed about each of those three potential scenarios, in a way that is easily accessible to the medical team at the time discussions about treatments need to take place (usually in a hospital ward, casualty or intensive care unit) because a sudden serious event has occurred.

PAC-Plan can include specific plans for managing (eg) pain, seizures or other symptoms, or 'Wishes' documents. Those plans are referred to in the PAC-Plan as modules.

*1.2. When should these discussions take place ?*

As a general rule, as early in the course of an illness as possible, because it offers the greatest opportunity to explore what might happen as the child's illness progresses. The right time to introduce the PAC-Plan process depends on the needs of the individual child and family.

*1.3. Who can use the PAC-Plan ?*

Any member of the Healthcare Team can take the lead in the PAC-Plan process, working in collaboration with colleagues. The child's main consultant should usually be involved in the discussions but does not have to take the lead at all times.

*1.4. Is it legally binding ?*

No. The document records your discussions, **but it does NOT AT ALL mean you cannot discuss those issues again, or change your mind at some point in the future.** Only the section relating to permission to disseminate the information represents a form of consent. We do suggest the document is signed by both consultant and patient or family. That makes it more likely the document will be acted on, but it is not strictly necessary, and some families never feel able to sign it. There is still considerable value in the PAC-Plan discussions, and in completing the rest of the document as a record.

*1.5. Will I have a chance to discuss these issues again ?*

Yes. You can ask to have these discussions again at any time. Ideally they should be discussed every 6 – 12 months anyway, even if there have been no changes.

**Paediatric Advance Care Plan (PAC-Plan)**  
Version 2.3

Name:  
NHS no:  
DOB:  
Address:

**Section 2: Background to this review**

2.1. Date first completed: ..... by .....  
Date last amended: ..... by .....  
Date to be reviewed: ..... by .....  
(usually < 12 months)

**2.2 Associated documents**

Other documents can form an important part of care at the end of life (eg seizure protocol, symptom control plan, respiratory care plan, organ donation forms and local 'wishes' documents). The following additional documents are associated with this Plan:

1.	2.	3.	4.
5.	6.	7.	8.

**2.3 The Plan was discussed with:**

- ☐ Patient  
☐ Mother/ Father  
☐ Other family, especially grandparents  
☐ Other e.g. nurse/respice/key worker  
☐ Local authority      ☐ Local authority has overriding parental responsibility.

**Paediatric Advance Care Plan (PAC-Plan)**  
*Version 2.3*

Name:  
NHS no:  
DOB:  
Address:

**2.4. Background information (including diagnosis, significant problems, usual level of health and well-being and reason for completing PAC-Plan at this particular time).**

**Paediatric Advance Care Plan (PAC-Plan)**  
Version 2.3

Name:  
NHS no:  
DOB:  
Address:

**Section 3: About other people in the family**

**3.1 Whom to call.**

This should be the name of the professional the child or family would want to be contacted first if there were a sudden and severe deterioration.

Name of person to call	Contact number

**3.2. Parents/ Main Carers (these should be the people who usually care for the patient).**

Name	Relationship to child	Parental responsibility? Y/N	Contact telephone number

**3.3 Who can give consent.**

The patient to whom this PAC-Plan refers is:

- ☐ A child who is 'Gillick competent' and can give consent on his/her own behalf.
- ☐ A child whose parents or guardian have parental responsibility and can give consent on his/her behalf.
- ☐ Someone with capacity under the 2005 Mental Capacity Act (MCA), who can give consent on his/her own behalf.
- ☐ Someone who lacks capacity under the MCA in whom best interests must be decided according to the MCA.
- ☐ Subject to other legal protection e.g. care order, court decision.

**Paediatric Advance Care Plan (PAC-Plan)**  
Version 2.3

Name:  
NHS no:  
DOB:  
Address:

**Section 4: Planning ahead**

Life-limiting conditions in childhood often cause a slow deterioration over many months or even years. Sometimes, however, there can be sudden illnesses that are serious enough to pose an immediate threat to life. Often these involve the breathing. Some can be reversed with the help of medical interventions. Others can't, or else can only be reversed by treatments that would be too unpleasant to bear. The purpose of this section is to explore the most appropriate treatment for each of those possibilities.

**BRIEF detail of medical condition (please note that this section of the PAC-Plan may be all that is seen by police and ambulance crew at the scene. Information in this box should summarise box 2.4)**

- 
- 
- 
- 
- 
- 
- 

**4.1: Management of a sudden, severe deterioration caused by something that can be reversed:**

This might include a problem during anaesthesia or an episode of choking in which there are medical interventions that can resolve the problem without being unbearable for the patient.

- ☐ Under these circumstances, all appropriate measures should be taken to reverse the problem.

**4.2: Management of slow, life-threatening deterioration:**

NB Comfort and support of child and family, and attention to management of symptoms (see symptom control module where appropriate) are part of routine care in all patients.

- ☐ Transfer to .....(preferred place of care).
- ☐ Transfer to high dependency unit.
- ☐ Use of non-invasive ventilation.
- ☐ Use of invasive intubation and ventilation (ie transfer to intensive care unit environment).

**Paediatric Advance Care Plan (PAC-Plan)**  
Version 2.3

Name:  
NHS no:  
DOB:  
Address:

**4.3: Management of a sudden, severe deterioration that cannot be reversed, or could only be reversed by treatments that are unpleasant for the patient:**

NB Comfort and support of child and family, and attention to management of symptoms (see symptom control module where appropriate) are part of routine care in all patients.

- ☐ Comfort measures only; no medical attempt to reverse the problem.

In addition to comfort measures as above:

- ☐ Suction upper airway, and other airway clearance techniques.
- ☐ Oxygen via face mask or nasal cannulae if it helps symptoms.
- ☐ Airway management including oral / nasopharyngeal airway if it helps symptoms.
- ☐ Mouth to mouth (or bag-and-mask) for five inflation breaths.
- ☐ Call 999 and transfer to ..... Hospital
- ☐ Give fluids and drugs intravenously.
- ☐ If that is impossible, give fluids and drugs via intraosseous needle into the bone.
- ☐ Consider transferring to high-dependency or intensive care environment.
- ☐ Consider putting a tube into airway and attaching it to a ventilator. That would mean transferring to intensive care.
- ☐ If the heart stops, consider attempts to get it started again using chest compressions or an electric defibrillator. That would also mean endotracheal tube and intensive care.

The PAC-Plan document provides a guide in providing care for this child in the event of a deterioration at the end of life. It is compiled in detailed discussions with a child, young person and/or their family. But those discussions cannot predict all eventualities. Notwithstanding the preferences recorded in this document, individual professionals are obliged to use their professional judgment to act in the best interests of the child, and to instigate further discussions regarding treatment if situations change.

**4.4: Organ donation**

Although organ donation is not always possible for children who have life-limiting conditions, all families should be offered the opportunity to discuss it with the local organ donation lead nurse (pager 07659591889).

- ☐ We have discussed this, and are not planning to take it any further.
- ☐ We have discussed this, and will contact the lead nurse on ..... (contact number). Please see organ donation module.

**Paediatric Advance Care Plan (PAC-Plan)**  
Version 2.3

Name:  
NHS no:  
DOB:  
Address:

**Section 5: Agreement with discussions**

**5.1 PAC-Plan lead (person leading on discussions eg specialist nurse)**

Signature: \_\_\_\_\_ Designation: \_\_\_\_\_

Name (PRINT): \_\_\_\_\_ Date: \_\_\_\_\_

**5.2 Senior Clinician's agreement ("I support this Paediatric Advance Care Plan"):**

Signature: \_\_\_\_\_

Designation: \_\_\_\_\_ GMC No: \_\_\_\_\_

Name (PRINT): \_\_\_\_\_ Date: \_\_\_\_\_

*A consenters signature supports that this document is an accurate representation of discussions held with named professionals to date. It is not binding. Discussions within the PAC-Plan can be revisited at any time and should be reviewed regularly.*

**5.3 Child or young person's agreement**

I have discussed the treatment and care outlined in this PAC-Plan with the appropriate professionals. I confirm that the Plan accurately represents the wishes I have for care and treatment for me..... ( name of child/young person)  
I understand that before any of the treatment commences I will be asked (wherever possible) whether I still consent to it.

Child/ young person signature: \_\_\_\_\_ Date: \_\_\_\_\_

**5.4. Parent or Guardian's agreement**

I/We have discussed the treatment and care outlined in this PAC-Plan with the appropriate professionals . I/We confirm that the Plan accurately represent the wishes I /we have for care and treatment for .....(name of child/ young person)  
I/we understand that before any of the treatment commences I / we will be asked whether I /we still consent (s) to it.

Name & signature: \_\_\_\_\_ Date: \_\_\_\_\_

**5.5. Statement of interpreter (where appropriate)**

I have interpreted the information above to the child/young person/parent to the best of my ability and in a way in which I believe the child/young person/parent can understand.

Name & signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Paediatric Advance Care Plan (PAC-Plan)**  
Version 2.3

Name:  
NHS no:  
DOB:  
Address:

**Section 6: Permission to share information with others**

**6.1 We will send copies of this Plan to:**

	Yes/No and initial added by Consentee	
Local PAC-Plan coordinator (responsible for dissemination)		
Parents/Guardians		
Hospital notes		
Local Hospital paediatrician(s)		
Community paediatrician		
GP		
GP out of hours service		
Other Hospital departments Children's Assessment Unit		
Community Nurses including Clinical nurse specialists		
(Audit file) (With child/young person/ parental consent)		
School health nursing team		
Social Worker or Special Needs Health Visitor		
Paediatric Oncology Outreach Nurse Specialist		
Children's Hospice		
School/ College Head teacher (with consent to share with school staff)		
Other e.g Social Care, short break care provider		
Adult services / transition team		
Welsh Ambulance NHS Trust Directed to Deputy Director of Medical and Clinical Services / Consultant Paramedic and the Named Professional Safeguarding Children.		Plan will be sent via post, secure email or via a safe haven fax. In the first instance phone 01792 315884 to inform the Safeguarding Team that Plan is being sent and by what method
Police		Police: North Wales 01407 724469 South Wales 01656 305944 Dyfed Powys 01267 226370 Gwent 01495 745590  Out of hours: Local Public Protection Unit Tel 101 <i>The Police will be informed of Plan's existence, but they will not usually receive a copy of it.</i>

**Paediatric Advance Care Plan (PAC-Plan)**  
Version 2.3

Name:  
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DOB:  
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Parents/Guardians		
Hospital notes		
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Community paediatrician		
GP		
GP out of hours service		
Other Hospital departments Children's Assessment Unit		
Community Nurses including Clinical nurse specialists		
(Audit file) (With child/young person/ parental consent)		
School health nursing team		
Social Worker or Special Needs Health Visitor		
Paediatric Oncology Outreach Nurse Specialist		
Children's Hospice		
School/ College Head teacher (with consent to share with school staff)		
Other e.g Social Care, short break care provider		
Adult services / transition team		
Welsh Ambulance NHS Trust Directed to Deputy Director of Medical and Clinical Services / Consultant Paramedic and the Named Professional Safeguarding Children.		Plan will be sent via post, secure email or via a safe haven fax. In the first instance phone 01792 315884 to inform the Safeguarding Team that Plan is being sent and by what method
Police		Police: North Wales 01407 724469 South Wales 01656 305944 Dyfed Powys 01267 226370 Gwent 01495 745590  Out of hours: Local Public Protection Unit Tel 101 <i>The Police will be informed of Plan's existence, but they will not usually receive a copy of it.</i>

**Paediatric Advance Care Plan (PAC-Plan)**  
Version 2.3

Name:  
NHS no:  
DOB:  
Address:

**6.2 Consent to Information Sharing**

I agree to the sharing of information contained within this advance and emergency care pathway with the agencies listed above (agreement confirmed by 'yes' and initial). I understand that withholding consent to sharing of information may limit the utility of the ECP. All the information that will be shared and the reasons why have been explained to me. I have had the opportunity to discuss any issues arising from this matter.

Signature: \_\_\_\_\_ (Child/young person/Parent /Guardian)\*

Name (PRINT): \_\_\_\_\_ Date: \_\_\_\_\_

Second signature where needed: \_\_\_\_\_ (Parent /Guardian)\*  
(eg if consentee above is a child):

Name (PRINT): \_\_\_\_\_ Date: \_\_\_\_\_

\*Delete as appropriate

(Or, if patient is over sixteen years of age:

This patient has been assessed under the MCA and is considered to lack capacity. In accordance with MCA, the Lead Consultant has considered the best interests of the patient and, after appropriate consultation set out that Act considers it to be in the patient's best interests for the information to be shared with the people/organisations set out above.

Signature: \_\_\_\_\_

Name (PRINT): \_\_\_\_\_ Date: \_\_\_\_\_ )

## Policy



**PAEDIATRIC ADVANCE CARE PLAN (PAC-PLAN) POLICY FOR PATIENTS UNDER 18 YEARS OF AGE WITH LIFE THREATENING OR LIFE LIMITING ILLNESS**

<b>Policy</b>	<b>Procedure</b>	<b>Protocol</b>	<b>Guideline</b>
<input type="checkbox"/> YES	<input type="checkbox"/> NO	<input type="checkbox"/> NO	<input type="checkbox"/> NO

Classification of Document: Clinical  
 Area for Circulation:  
 Reference Number:  
 Version Number: 1  
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Author Name and Job Title: PAC-Plan Development sub-group of All-Wales Network in Paediatric Palliative Care  
 Responsible Officer: Richard Hain  
 Name and Job Title: Clinical Lead, Paediatric Palliative Care  
 Details of lead/responsible: Chair  
 Group/Committee: All-Wales Network in Paediatric Palliative Care  
 Consulted Via: All-Wales Medical Directors' Group  
 Clinical Ethics Committee  
 Cardiff and Vale of Glamorgan Local Safeguarding Children Board (formerly UHB Safeguarding Children's Board)  
 Resuscitation Group

Ratified by:  
 Chairman of Validating Body: Date Issued:

Review Details: Every 3 years

Version Number	Date of Review	Reviewer Name	Completed Action	Approved By	Date Approved	New Review Date

Reference Number: Version Number: 1(draft 13)  
 Paediatric Advance Care Plan (PAC-Plan) Policy for Children with Life Threatening or Life Limiting Illness

Original Approval Date:

**Disclaimer**

When using this document please ensure that the version you are using is the most up to date either by checking on the UHB database for any new versions. If the review date has passed please contact the author  
**OUT OF DATE POLICY DOCUMENTS MUST NOT BE RELIED ON**

## CONTENTS

Section	Page
1.0 Executive Summary	3
1.1 Purpose of Policy	3
2.0 Introduction	3
3.0 Policy Statement	4
4.0 Aims of the Policy	4
5.0 Scope	4
6.0 Definition of Terms	5
6.1 Life-limiting Conditions	5
6.2 Life-threatening Conditions	5
6.3 End of Life	5
6.4 Paediatric Advance Care Planning	5
6.5 Child	6
6.6 CPR	6
7.0 Roles and Responsibilities	6
7.1 Health Board	6
7.2 Resuscitation Committee	6
7.3 Resuscitation Service	7
7.4 Child Health Paediatric Advance Care Planning Focus Group	7
7.5 Divisional Directors and Line Managers	7
7.6 Individual Staff Members	7
8.0 Paediatric Advance Care Planning Decision Making	7
8.1 Paediatric Advance Care Planning for Children/Young People with Life threatening/Life limiting Conditions – A New Standard of Care	8
8.2 Timing of Initiating the Advance Care Planning Process	8
8.3 Ethical Issues in Advance Care Planning	8
8.4 When to Attempt CPR	10
8.5 Refusal of Treatment	10
9.0 Temporary Suspension of a PAC-PLAN Order Recorded in an PAC-PLAN	11
10.0 Responsibility for Advance Care Planning	11
11.0 Communicating Paediatric Advance Care Planning Decisions within Health	12
12.0 Recording Paediatric Advance Care Planning (PAC-PLAN) Decisions	13
13.0 Communicating Paediatric Advance Care Planning Decisions to Multiagency Team	13
13.1 Ambulance Service	13
13.2 General Practitioner	14
13.3 Education	14
13.4 Child Health & Disability (CHAD) Social Services	14
13.5 The Coroner	15
13.6 Police	15
13.7 Ty Hafan Children's Hospice	16

Reference Number:

Version Number: 1(draft 13)

Paediatric Advance Care Plan (PAC-Plan) Policy for Children with Life Threatening or Life Limiting Illness

Page 3 of 23

Original Approval Date:

14.0	Reviewing the Paediatric Advance Care Planning (PAC- PLAN) Decision	16
15.0	Raising Awareness of the Paediatric Advance Care Planning Policy	17
16.0	Review of the Advance and Emergency Care Pathway Policy	17
17.0	Implementation	17
18.0	Resources and Funding	18
19.0	Audit	18
20.0	Equality	18
21.0	Contributors	18
22.0	References	19

## 1. EXECUTIVE SUMMARY

### 1.1. Purpose of Policy

For every person there comes a time when death is inevitable. For a child with life threatening or life limiting illness that time is expected to arrive during childhood.

The purpose of the Paediatric Advance Care Plan (PAC-Plan) policy is to outline the legal and ethical standards for planning patient care and decision making at the end of a child's life, particularly in relation to interventions that might delay death at the cost of pain or discomfort to the child.

## 2.0 INTRODUCTION

"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, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms; provision of short breaks, and care through death and bereavement."<sup>1</sup>

The palliative phase for children is often longer than for adults with specialist support needed over years rather than months.

Paediatric palliative care services must meet the needs of children and young people with a wide range of differing conditions including neurodisability, neurodegenerative conditions and chronic conditions such as cystic fibrosis, cardiac disease and cancers.

Decisions regarding interventions at the end of life should form part of a holistic end of life planning for a child or young person with a life threatening or life limiting illness.

Use of a Paediatric Advance Care Plan (PAC-Plan) includes options regarding resuscitation should alert the beginning of a process of discussion and individualised care for that particular child and family with the condition.<sup>2</sup>

It is vital to encourage the involvement of the patient, their family, the health care team and people close to the patient in decision making, and to ensure the communication of decisions to all relevant health and multiagency professionals. (GP, Community Nursing service, Respite, Education, Social Services, Ambulance, Police, Coroner, Bereavement Services)<sup>3</sup>

### 3.0 POLICY STATEMENT

Cardiff and Vale University Health Board is committed to implementing the guidance for Paediatric Advance Care Planning for children and young people with life threatening or life limiting illness as supported by the reference list. This policy should be read in conjunction with the Cardiff and Vale University Local Health Board Policy on DNAR in adults<sup>4</sup>, and Guidance from RCPCH<sup>2,8</sup>, NICE, the GMC, BMA, RC (UK), RCN.<sup>3</sup>

The purpose of the Paediatric Advance Care Planning policy is to outline the legal and ethical standards for planning patient care related to the terminal phase of a child or young person's life; it should include plans about cardiopulmonary resuscitation and admission to intensive care for mechanical ventilation.

### 4.0 AIMS OF POLICY

- To implement a consistent approach to Advance Care Planning in children.
- To ensure children receive appropriate and effective resuscitation when necessary and without delay
- To ensure children are treated with dignity and their human rights are respected<sup>5</sup>
- To ensure appropriate, correct and respected application of United Nations Convention on Rights of the Child<sup>6</sup>
- **To promote current best practice in children's palliative care and specifically in the area of advance care planning based on current national guidance from ACT<sup>1</sup>, Royal College of Paediatrics and Child Health<sup>7</sup>, Royal College of Physicians<sup>2,8</sup>, IMPaCCT group<sup>9</sup>, Department of Health<sup>10</sup>, General Medical Council<sup>11</sup>, Welsh Assembly Government<sup>12</sup>, National Service Framework for Children<sup>13</sup>.**
- **To comply with Department of Health requirements**
  - To provide support for clinical staff
  - To provide written information for children and relatives
  - To satisfy legal and professional requirements
  - To minimise clinical risk, litigation and material loss
  - To comply with UHB requirements for formal organisation-wide policies.
  - To ensure the PAC-Plan procedures are monitored and audited
  - To facilitate improving end of life care as a key performance indicator of all NHS Health Boards and Trusts in Wales

## 5.0 SCOPE

All members of staff who are involved in planning of patient care, review and decision making in relation to children or young people with life threatening or life limiting illness requiring paediatric advance care planning with regards to active treatment and/or symptom control and cardiopulmonary resuscitation.

## 6.0 DEFINITION OF TERMS

**6.1** 'DNAR' ('Do Not Attempt to Resuscitate') was a term historically used to record a decision that in the event of a sudden deterioration resulting in cardiorespiratory failure, no resuscitation would be carried out.<sup>4</sup> Developed in adults, 'DNAR' is not appropriate in the context of a child/young person with life threatening or life limiting illness, for three main reasons:

- DNAR is often seen to represent a unilateral decision on the part of the doctor or healthcare team. Where there are multiple family members and carers involved, as is usual in the care of a child with a life-limiting condition, other views (especially those of parents) must be solicited before such a decision is made.
- DNAR offers only binary options ("do everything/do nothing") and its scope is limited to cardiopulmonary resuscitation, rather than to life-saving or life-sustaining treatments more generally. In children, it is more important to set out the range of options that have been discussed and an indication that consensus has been reached. Effective communication is key to the success of paediatric advance care planning.
- Parents do not have the same right to refuse treatment on behalf of their child as an adult patient would have to refuse her own treatment. Conclusions about end of life care in children represent preferences on the part of a child, young person and/or their family. that are agreed by healthcare professionals to be reasonable.

### 6.2 Life-limiting Conditions

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children or young people are expected to die before reaching adulthood. They typically cause progressive deterioration, rendering the child increasingly dependent on parents and carers as adulthood approaches<sup>1</sup>.

### 6.3 Life-threatening Conditions

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as children with cancer.<sup>1</sup> Children or young people in long-term remission or following successful curative treatment are not included.

### 6.4 End of Life

The 'end of life' phase ends in death. Definition of its beginning is variable according to individual child/young person/family and professional

Reference Number:

Version Number: 1(draft 13)

Paediatric Advance Care Plan (PAC-Plan) Policy for Children with Life Threatening or Life Limiting Illness

Page 7 of 23

Original Approval Date:

perspectives. In some cases it may be the child/young person or family who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the patient. Since it is rarely clear at the outset of an acute deterioration whether or not it will result in death, it is usual for children with complex chronic conditions to have several 'end of life' episodes.

### **6.5 Paediatric Advance Care Planning**

Paediatric advance care planning begins when a child or fetus is at risk of life threatening deterioration, whether following an acute event or a more gradual decline. It includes discussing life-sustaining (active) treatments and establishing long-term care goals. The child/young person, their parent/carers and the child's paediatrician should agree on the most appropriate care in an emergency or slow deterioration and sign a pathway form (see Appendix 1). Paediatric advance care planning may conclude that any of a range of options be in the child/young person's best interests, from full resuscitation including invasive ventilation through active treatment which might be life-prolonging (e.g. IV antibiotics) but stops short of invasive ventilation support or CPR, to measures where the aim of treatment is to relieve symptoms without prolonging life.

### **6.6 Child**

There is a clear legal distinction, in terms of treatment decision-making between those who are 16 years of age and over and those who are under 16. In this Policy, reference to a child means a patient who is under 16 years of age. Patients who are 16 and 17 years old are referred to as young people. Children are presumed not to be competent to make their own treatment decisions, unless they have been assessed to be *Gillick* competent. In contrast, patients aged 16 years and over are presumed to have capacity to make their own decisions.

A child or young person may have a PAC-Plan or begin the discussions about completing a PAC-Plan at any point in time while they remain under the primary care of a lead child health professional.

Work is under way to develop a PAC-Plan for young adults with life-limiting conditions who lack capacity. Professionals should be aware that the legal framework and systems for assessing capacity are different for adults. Professionals should seek appropriate advice regarding this matter.

### **6.7 Cardiopulmonary Resuscitation (CPR)**

Cardiopulmonary Resuscitation: may include artificial respiration chest compressions and defibrillation in an attempt to restart the heart.<sup>4</sup>

## **7. ROLES AND RESPONSIBILITIES**

Cardiff and Vale UHB aims to comply with national guidance to healthcare professionals both through the development of this policy and the production of an information leaflet for children and relatives.

### **7.1 Health Board**

The UHB Board carries overall responsibility for Cardiff and Vale UHB. It has delegated powers from the National Assembly for Wales in respect of the ownership and management of hospitals and other health facilities; it is responsible for the performance of the UHB. The Chief Executive must ensure the UHB has an agreed Resuscitation Policy that respects Children's Rights and that any decisions made by staff are informed via the Paediatric Advance Care Planning policy and relevant child/young person/family information.

### **7.2 Resuscitation Group**

The UHB Resuscitation Group, led by its chairperson, meets on a regular basis. Its role is to ensure that UK Resuscitation Council guidelines for the resuscitation of victims of cardiopulmonary arrest are implemented effectively. Group members should be conversant with contemporary issues related to new developmental knowledge, and be aware of the need to specify them appropriately for the particular issues of children through discussion with specialists in paediatric end of life and intensive care.

### **7.3 Resuscitation Service**

The Resuscitation Service is answerable to the Resuscitation Group in terms of its clinical lead. It is responsible for implementing decisions made by the Resuscitation Group and promoting good practice primarily through training and audit. The Resuscitation Service is responsible for assessing those it teaches and ensuring that they meet standards that reflect UK Resuscitation Council guidelines. The Resuscitation Service develops policies using guidance to ensure full multidisciplinary representation. It monitors cardiac arrest outcome and team response as well as adherence to resuscitation policies (including PAC-Plan policy). The Senior Resuscitation Practitioner will maintain, manage and develop the service, within available resources, to meet the needs of the Health Board.

### **7.4 All-Wales Network in Paediatric Palliative Care**

The PAC-Plan subgroup is convened under the All-Wales Network in Paediatric Palliative Care. The Network meets on a regular basis. Members should be conversant with contemporary issues related to new developmental knowledge and review and update this policy annually through regular clinical governance procedures.

### **7.5 Clinical Board Directors and Line Managers**

While the UHB has the responsibility to ensure that resuscitation policies and relevant patient information are developed through the UHB Resuscitation Service, those who manage staff, particularly clinical staff, have a responsibility to ensure that staff and, where relevant, children and their relatives have access to and understand resuscitation policies, especially the PAC-Plan policy.

### 7.6 Individual Staff Members

While the UHB has a responsibility to provide a Resuscitation Service and its managers are responsible for ensuring staff have access to and understand resuscitation policies and relevant patient information leaflets, each individual is responsible for their own actions and professional practice. Paediatric health care practitioners have an obligation to educate themselves about this aspect of medical care. Individual staff members should familiarise themselves with UHB resuscitation policies and, with respect to the PAC-Plan policy ensure that children and their families have access to and understand it. Staff must respect patient rights to confidentiality whilst ensuring that decisions relating to PAC-Plan are communicated to appropriate colleagues with informed consent.<sup>14</sup>

## 8. PAEDIATRIC ADVANCE CARE PLANNING DECISION MAKING

Advance Care Planning is an extension of usual discussions about plans for treatment, which have conventionally focused on curative measures and on what will be provided rather than what will not. Paediatric advance care planning broadly encompasses both short-term and long-term health care goals and treatments. It may include the drafting of formal advance options, which specify what treatments will or will not be provided for the child/young person. The benefits of Advance Care Planning **are** both procedural, in that two-way communication is improved, as well as substantive, in that the actual details of the plans for care are clarified. When paediatric advance care planning is executed well it ensures that shared goals of care, be they curative or palliative, are aligned with the planned course of treatment.

### 8.1 Advance Care Planning for Children/Young People with Life Threatening or Life Limiting Conditions – a New Standard of Care

Advance care planning in paediatrics is most important among children with life-limiting or life-threatening conditions. Among such children, the expected mode of death is often an acute deterioration in respiratory, brain or bowel function. The stimulus for discussion is usually recognition that some interventions, especially those associated with intensive care, will do harm to the child that cannot be justified because the chance that they will prolong the child's life is too small. Such discussions represent a transition from a curative to a palliative focus of care that can be abrupt if the discussions are left too late. Health care providers should be aware that palliative care is appropriate at any point following diagnosis of a life-limiting or life threatening condition, and can proceed alongside treatments which may have cure as their goal.

### 8.2 Timing of Initiating the Advance Care and Emergency Pathway Process

- As a general rule, the earlier PAC-Planning begins in the trajectory of an individual child's illness, the better prepared the family and healthcare team can be at the time of the child's death.

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Reference Number:

Version Number: 1(draft 13)

Paediatric Advance Care Plan (PAC-Plan) Policy for Children with Life Threatening or Life Limiting Illness

Page 10 of 23

Original Approval Date:

- Each family is different, however, and the most appropriate timing will depend on the readiness of the family to engage with the process. A significant minority of families will never be willing to do so, while others will feel comfortable with having the discussions but will never sign the form.
- PAC-Plan discussions take place over many weeks and months. Even in the paediatric intensive care setting, in which decision-making often occurs on a compressed timeline, one Canadian study<sup>15</sup> found that two or more meetings were required to achieve consensus in 46% of cases involving decisions to forego life-sustaining therapy.
- Effective communication includes being open and available for feedback, having ongoing discussions and re-evaluating treatment goals.
- Emotional and psychological needs of child/young person/family must be considered at all times. Available counselling and psychological support services should be accessed when appropriate e.g. parent counselling service.

### 8.3 Ethical issues in Advance Care Planning

The ethical principles that underlie Advance Care Planning include respect for autonomy, beneficence, non-maleficence and justice. Any course of action should only be undertaken when the benefit to the child/young person proportionately outweighs the burden<sup>16</sup>. Since it is not possible precisely to predict benefits and burdens, the PAC-Plan is designed to encourage 'parallel planning'; that is, an exploration of different scenarios that might occur at the end of life, and a record of preferences in each. Those preferences result from values as well as medical facts, and the PAC-Plan accommodates views that are subjective. Health care professionals should be aware of differences in how burden is perceived, looking from the perspective of the child/young person in isolation versus being embedded in a family unit. It may even be difficult to separate the interests of the child from those of their caregivers and extended family members. The best interests of the child, however, should be of paramount consideration<sup>17</sup>.

#### 8.3.1 Assessment of Best Interest.

- (1) General guiding principles are set out by the General Medical Council (GMC) 'Respect for human life and best interests, (see paragraphs 9-11). There is specific guidance in children<sup>11</sup> (0-18 years: guidance for all doctors. General Medical Council 2007, paragraphs 12-13)  
An assessment of best interests will include what is clinically indicated in a particular case. You should also consider:
  - a) The views of the child or young person, so far as they can express them, including any previously expressed preferences
  - b) The views of parents
  - c) The views of others close to the child or young person
  - d) The cultural, religious or other beliefs and values of the child or parents

- e) The views of other healthcare professionals involved in providing care to the child or young person, and of any other professionals who have an interest in their welfare
- f) Where there are a number of options, that which will least restrict the child or young person's future options should be selected.

This list is not exhaustive. The weight attached to each point will depend on the circumstances, and all other relevant information should be considered. One should not make unjustified assumptions about a child or young person's best interests based on irrelevant or discriminatory factors, such as their behaviour, appearance or disability.

In cases of acute critical illness where the outcome of treatment is unclear, as for some children who require intensive care, survival from the acute crisis would be regarded as being in the patient's best interests<sup>18</sup>

### 8.3.2 Capacity to Consent

Guidance is set out by the GMC re decisions on capacity to consent (see paragraphs 24-29)<sup>11</sup> (see Paragraph 68-72)<sup>18</sup> See also the UHB's Consent to Examination or Treatment Policy.

The capacity of paediatric patients to consent ranges from those who lack capacity altogether to those who are fully capable of consent. The latter defines the mature or 'Gillick Competent' minor, who is legally not an adult according to chronological age criteria, but has the cognitive ability to consider treatment choices and alternatives and weigh the consequences and, other than by age, would be considered to have capacity as defined by the Mental Capacity Act 2005.

The authority of the expressed preferences of a Gillick competent minor are essentially those of an adult and cannot usually be overridden, even if they are seen to be perverse or irrational, without express permission from the Court.

Where minors lack 'Gillick Competence' but are capable of expressing a preference, that preference is important and should be given weight in end of life decision-making, even if it is ultimately necessary to override it on the grounds of the child's interests.

A Scandinavian study<sup>19</sup> found that a quarter of parents regretted not talking about death with their child who was dying of cancer, suggesting that one of our responsibilities is to help parents address this issue. Providing information is consistent with the duty to be honest with our children. We respect their dignity by only administering treatments that they have freely chosen and desire.

#### 8.4 When to Attempt CPR

Where no explicit advance decision has been made about the appropriateness or otherwise of attempting resuscitation prior to a patient suffering cardiac or respiratory arrest, and the express wishes of the child and/or family are unknown and cannot be ascertained health professionals should make all reasonable efforts to attempt to revive the patient.

Ideally, decisions about whether to attempt to resuscitate an individual are made in advance as part of overall care planning for that patient and, as such, are discussed with the patient along with other aspects of future care. Neither children, nor those close to them, can demand treatment that is clinically inappropriate.

In an emergency situation and in the absence of the patient's consultant/GP, the doctor on duty should attempt CPR unless:

- The Paediatric Advance Care Planning suggests alternative management
- The patient is clearly in the terminal phase of illness
- Sufficient information is available to make a judgement that CPR would not be in the child/ young person's best interest.

Where CPR may restart the heart and breathing for a sustained period but there are doubts about whether this is in a child's best interest, the views of the family, child or young person should be taken into consideration in deciding whether it should be attempted.<sup>3</sup>

#### 8.5. Refusal of Treatment

- Adults with parental responsibility are the usual proxy decision makers for children who are unable to decide for themselves.
- Whenever possible, children or young people should be fully involved in all decisions affecting them, even if they are not Gillick competent or lack capacity.<sup>11</sup>
- The views of children and young people must be taken into consideration when making decisions about end of life interventions, even when they are not able to make the decisions for themselves.
- Competent children can consent to treatment in England and Wales<sup>9</sup>.
- Refusal of treatment by a Gillick-competent minor cannot usually be overturned without express permission from the Courts<sup>11</sup>. In the past, the Courts typically supported the treatment preferences of parents over those of the child, but that is becoming increasingly uncommon and should not be assumed.
- Parents cannot require doctors to provide treatment contrary to their professional judgement, but doctors must try to

accommodate parental wishes as far as they are compatible with the child's best interests.

- If there is disagreement between those with parental responsibility and the health care team, advice from the Clinical Ethics Committee and/or legal advice must be sought in a timely fashion <sup>11</sup>.

#### **9. TEMPORARY SUSPENSION OF A PAC-PLAN ORDER RECORDED IN AN ADVANCE & EMERGENCY CARE PATHWAY**

- The PAC-Plan discussions include exploration of the possibility that cardiac or respiratory arrest will occur in a child with a life-limiting condition, but from a readily reversible cause such as choking, induction of anaesthesia, anaphylaxis or blocked tracheostomy tube. In such situations CPR will usually be appropriate while the reversible cause is addressed. A specific example is where an intervention carries the risk of cardiopulmonary arrest. General or regional anaesthesia, for example, may cause cardiovascular or respiratory instability that should usually be treated, irrespective of the conclusions recorded in a PAC-Plan.
- It is good practice to review the PAC-Plan as part of the clinical preparation for surgery, and again once the child has returned to base-line health afterwards.

#### **10. RESPONSIBILITY FOR PAEDIATRIC ADVANCE CARE PLANNING DECISION MAKING**

- The conclusions recorded on a PAC-Plan are to guide clinicians making decisions about the appropriateness or otherwise of certain interventions at the end of a child's life. They are not legally binding, and do not replace discussions with patients/families at the actual time of an acute deterioration.
- They do not obviate the need to make a decision in the interests of the child at the point of an acute deterioration. 'Standard rules' or 'blanket policies' that restrict interventions for reasons other than the interests of the child at the time are unlawful and cannot apply.
- Overall responsibility for decisions about what interventions are appropriate rests with the physician in charge of the patient's care, who may be the specialist with primary responsibility for the most significant illness at the time (e.g. oncologist for a child/young person with cancer).
- Where responsibility for a child/young person's care is shared (e.g. between general paediatrics and paediatric palliative care) decisions should be made together. However, one individual

should take the lead in the PAC-Plan process, ensuring discussions are properly recorded and communicated to those who need to be aware of them.

- If it becomes clear that there is important disagreement within the team (or between the team and parents, for example), legal advice should be sought. from the Clinical Ethics Committee and/or a legal representative. This should be timely enough to allow the possibility of resolution before a life-threatening episode.
- PAC-Plan conclusions must be based on reliable, up-to-date clinical guidelines.
- The language needs of children and their families must be met; interpreters should be used when necessary.
- Decisions about what interventions are appropriate should be undertaken in compliance with the Cardiff and Vale UHB's Policy Consent to Examination or Treatment Policy.<sup>21</sup>

#### **11. COMMUNICATING PAEDIATRIC ADVANCE CARE PLANNING DECISIONS**

- Decisions regarding PAC-Plans in children need to be clearly communicated to all involved with their care, for example; schools, hospice, respite carers, etc. Consent to share this information must be sought from the patient/ someone with parental responsibility for them/ in their best interests.
- A leaflet should be made available to children and people close to them explaining PAC-Plans, how decisions are made and what their involvement would be in the process.
- Any decisions about CPR should be communicated between health professionals whenever a patient is transferred between establishments, between different areas or departments of the same establishment, or is discharged home.
- Transfer of children between facilities: It is the responsibility of the clinical team caring for the patient to review the patient's resuscitation status at the earliest opportunity following transfer between healthcare settings or out into the community. This may mean review after transfer by the transferring lead clinician or handover to and review by receiving team (e.g. other speciality team neurology, respiratory, renal, cardiac, community Consultant).

#### **12. RECORDING PAEDIATRIC ADVANCE CARE PLANNING (PAC-PLAN) DECISIONS**

- All decisions relating to resuscitation should be clearly documented with the date of the decision and the reason for it.

- Any PAC-PLAN decision and the reasons for it must be recorded in the medical notes\*. The documentation must be dated and signed by the most senior member of the team.
- \*The use of the dedicated PAC-Plan form is recommended; this form should be completed and filed in the front of the medical notes.
- Any decision relating to attempting CPR should be clearly recorded in the nursing notes by the primary nurse or the most senior member of the nursing team whose responsibility it is to inform other members of the nursing team
- Any decision about the provision of attempted CPR must be readily accessible to all relevant health care professionals.
- In acute hospitals the consultant making the decision may delegate the communication of this decision to his/her colleagues.
- Where GPs make this decision, they are responsible for its appropriate dissemination.

### **13. COMMUNICATING PAEDIATRIC ADVANCE CARE PLANNING DECISIONS TO THE MULTIAGENCY TEAM**

#### **13.1. Ambulance**

- Clinical guidelines issued by the Joint Royal Colleges Ambulance Liaison committee (JRCALC) advise ambulance staff that they should always initiate CPR unless:  
There is a formal PAC-Plan conclusion, which has been seen by the ambulance crew, and the circumstances in which CPR may be attempted are consistent with the wording of the PAC-Plan conclusion; or the child/young person is known to be terminally ill and is being transferred to a palliative or terminal care facility (unless specific instructions have been received that CPR should be attempted)
- To enable the ambulance staff to comply with these guidelines, procedures must be in place to notify the ambulance staff of the child/young person's CPR status, and provide them with the necessary documentation before the transfer commences.
- If a child/young person is being transferred from hospital to a palliative care facility for terminal care then it is the responsibility of the transferring clinician to ensure that the ambulance crew have viewed a copy of the child/young person's PAC-Plan prior to transfer.
- If an ambulance crew is called to attend a child/young person with a PAC-Plan in the community – e.g. at home the ambulance control system will alert the crew that a PAC-Plan exists. The crew will receive no information about the contents of the PAC-PLAN; it will be the responsibility of the child/young person's

carer to show the crew the most up to date copy of the child/young person's PAC-Plan.

- The ambulance control system will only communicate information to the ambulance crew about the existence of a PAC-Plan if the 999 call is made from the child/young person's home address. If an ambulance is called from an address other than the home – e.g. school; it will be the responsibility of the child/young person's attending carer to show the crew the most up to date copy of the child/young person's PAC-Plan
- When attending the child/young person professionals must be aware that the patient, parents/carers of a child or young person with a PAC-Plan may change their mind and request resuscitation for their child.

### **13.2 General Practitioner (GP)**

- The child/young person's GP will be invited to contribute to the PAC-Plan planning process.
- It will be the child/young person's GP's responsibility to ensure that details of the individual's PAC-Plan are communicated to the Out of Hours GP service.
- It remains the GP's responsibility to ensure that the child is on the practice palliative care register information, so that the information available to the Out of Hours GP service is up to date and that they are in receipt of the child/young person's current PAC-Plan.

### **13.3. Education**

- Timely and sensitive use of the PAC-Plan should also facilitate discussion around the limitations of its use, for example in the school setting where education staff have a duty to call an ambulance and initiate resuscitation

### **13.4. Child Health and Disability (CHAD) Social Services**

- Any child/young person with a PAC-Plan is likely to have an appointed Special Needs Health Visitor (SNHV) or CHAD Social worker (SW)
- Some children/young people requiring a PAC-Plan would benefit from accessing the services of the National Youth Advocacy Service (tel. 029 2066 8956) to ensure their participation in decision-making is optimised.
- Advocacy needs may be discussed with the child/young person/family and their respective Special Needs Health Visitor or CHAD social worker
- It will be the responsibility of the named SW/SNHV to disseminate information about a PAC-Plan to respite carers other than Community Children's Nurses.

### 13.5. The Coroner

- The Coroner investigates all deaths the cause of which is unknown or unnatural. A child/young person with a PAC-Plan may die unexpectedly or the cause of their death may not be known. If a child/young person has a PAC-Plan this does not negate the need to involve the Coroner.
- Families should be made aware that if an ambulance is called to attend a child/young person's death the police and therefore also the Coroner will automatically be informed of the child/young person's death. The Coroner then has a duty to investigate the death.
- The aim of the Coroner's investigation is to establish the cause of a child/young person's death. This may only involve seeking this information from a doctor who knows this child. For deaths that occur out of hours this may not be possible until the next working day. If the cause of death is unclear from discussions with health professionals the Coroner may proceed to further investigations which may include a post mortem examination of the child/young person.
- If a death is being investigated by the Coroner the child/young person's body must reside in the local mortuary. The child/young person should not be washed or changed and equipment, such as indwelling tubes or lines must not be removed without her permission.
- Creating a PAC-Plan should provide an opportunity to prepare parents and carers for possible Coroner involvement when their child dies. It does not negate the need for a Coroner's investigation of an unexplained death.

### 13.6 Police

- When a child dies at home (or elsewhere in the community) the police may have a duty to investigate the circumstances of the death.
- The existence of a PAC-Plan cannot remove the obligations that the police have or limit their investigative responsibility. The police should be made aware at the earliest opportunity of the existence of such a PAC-Plan as this will assist information sharing between professionals and support the decision making process.
- Creating a PAC-Plan should provide an opportunity to prepare parents and carers for possible police involvement when their child dies.

### 13.7 Ty Hafan Children's Hospice

- The team at Ty Hafan Children's Hospice have a wealth of experience of caring for children/young people with life-limiting illnesses and their families; throughout life, through death and

into bereavement. The team are able to share this expertise with families and professionals.

- Ty Hafan uses its own advance care planning documentation with its children and young people when felt to be appropriate. The documentation includes planning for spiritual care and pre and post bereavement support. Such care should complement the Cardiff and Vale PAC-Plan.
- The Family Support team at Ty Hafan offer a 24-hour on call service to families. Ty Hafan could act as 1<sup>st</sup> contact for families in the event of their child dying outside of normal working hours when other professionals may not be contactable. This might involve the Ty Hafan family support worker supporting the family at home if needed and liaising with professionals from other agencies.
- In order for Ty Hafan to offer this service the child/young person does not need to be accessing the hospice already but Ty Hafan must hold an up to date copy of the child/young person's PAC-PLAN.
- All PAC-Plans drawn up for children/young people in Cardiff and The Vale of Glamorgan must be copied to The Assistant Director of Care at Ty Hafan, providing consent has been given for this. The family support team will then hold up to date information in order to support families and will monitor the need for annual review of PAC-Plans.
- If professionals need to access information from a child/young person's PAC-Plan outside of normal working hours and in the absence of being able to access any other copy of the PAC-Plan such as the parent-held copy, they could contact the family support team at Ty Hafan to access Ty Hafan's copy.
- The Ty Hafan family support team are contactable on Tel. (029) 20532200

#### 14. REVIEWING THE PAEDIATRIC ADVANCE CARE PLANNING DECISION

- PAC-Plan documentation must be reviewed regularly. The frequency of the review will be determined by the child/young person's health care needs and professional in charge and may be influenced by:
  - Changes in the child/young person's condition
  - Changes in patient or family wishes
  - Transfer from one facility to another
  - Changes in the consultant or GP in charge
- Every PAC-Plan document should include a review date.

- PAC-Plan discussions should occur early and regularly throughout the course of treatment, ideally before crises arise, and as the goals of care are clarified or change over time. Decisions should be reviewed on a regular basis and revised as necessary as the medical condition and knowledge of treatment and prognosis evolve.
- Paediatric palliative care professionals should be involved early in discussions of treatment goals. Discussions about palliative care should ideally take place well before the child is at imminent risk of dying.

#### **15. RAISING AWARENESS OF THE PAEDIATRIC ADVANCE CARE PLANNING POLICY**

At Health Board induction, all newly employed health professionals will be made aware of the Cardiff and Vale UHB paediatric advance care planning policy and their responsibilities according to the policy. Staff must have access to this document. The Resuscitation Service will provide this information. Existing staff will be made aware of the Cardiff and Vale advance care planning policy for children through the Resuscitation Service and attending regular health professional scheduled meetings.

#### **16. REVIEW OF THE PAEDIATRIC ADVANCE CARE PLANNING POLICY**

It is the responsibility of the Child Health Paediatric Advance Care Planning Focus Group in liaison with the Resuscitation Group of Cardiff and Vale UHB to review and update the PAC-Plan policy, taking into account new guidelines, changes in the law, and/or recommendations arising from audit following the implementation of the policy. Review of the policy will occur routinely once every three years and more frequently if required. These amendments will be presented to The Quality, Safety and Experience Committee

#### **17. IMPLEMENTATION**

All newly employed health professionals will be made aware of the Cardiff and Vale UHB policy on PAC-Plan and their responsibilities according to the policy at their local induction. Existing staff will be made aware of the policy through training and dissemination of this information to all appropriate Clinical Boards and managers in accordance with the management of policies and procedures for Cardiff and Vale UHB.

#### **18. RESOURCES AND FUNDING**

The policy will be distributed electronically and introduced to doctors as part of the in-house training programme when being appointed to work for Cardiff and Vale UHB. Full printed forms will be available as a download from the Intranet.

## 19. AUDIT

Compliance with this policy and the completion of PAC-Plan forms will be assessed through a process of spot-check audit. Professionals using the PAC-Plan will be required to complete an audit form and return this to St David's Children's Centre. Audit data will be examined by the Child Health Paediatric Advance Care Planning Focus Group and presented to the Children and Women Clinical Board at a Quality, Safety and Experience Meeting 12 months after the introduction of the PAC-Plan and then at regular intervals thereafter.

## 20. EQUALITY

An equality impact assessment has been undertaken to assess the relevance of this policy to equality and potential impact on different groups, specifically in relation to the General Duty of the Race Relations (Amendment) Act 2000 and the Disability Discrimination Act 2005, Equality Act 2010 and including other equality legislation. The assessment identified that the policy presented a low risk to the UHB.

## 21. CONTRIBUTORS

These have contributed to the original policy, or to the updated policy, or to both. Some have moved on to other roles since making their contribution.

Dr Richard Hain	Consultant Paediatric Palliative Medicine (CVUHB)
Dr Jo Griffiths	Consultant Paediatric Palliative Medicine (ABMU)
Dr Sian Moynihan	Consultant Community Child Health
Dr Charlotte Mellor	Paediatric Palliative Medicine SpR
Dr Michelle Jardine	Consultant Paediatric Intensive Care
Dr Helen Fardy	Consultant Paediatric Intensive Care
Dr Cath Norton	Associate Clinical Director Consultant Community Child Health
Dr Louise Hartley	Consultant Paediatric Neurologist
Dr Graham Shortland	Consultant Paediatrician
Cath Thompson	Assistant Director of Care , Ty Hafan
Liz Pendleton	Lead Nurse Community Children's Nursing Cardiff
Mary Glover	Senior Nurse Neonatal Unit
Dr J Calvert	Consultant Neonatologist
Carys Davies	Special Needs Health Visitor

Reference Number: Paediatric Advance Care Plan (PAC-Plan) Policy for Children with Life Threatening or Life Limiting Illness

Version Number: 1(draft 13)

Wendy Herbert	Head of Health Visiting
Diane Rogers	Head of Paediatric Physiotherapy Services
Nuala Mahon	Lead Nurse School Health
Dr Rhodri Lewis	General Practitioner
Chris Horrocks	Service Manager Child Health and Disability
Ms ME Hassell	HM Coroner for Cardiff and The Vale of Glamorgan
Mrs Hillary Valle	Parent representative

We would like to acknowledge the work of Neath Port Talbot Safeguarding Children's Board Management Group. The Cardiff and Vale PAC-Plan and Neath Port Talbot ACP have been developed as comparable documents with the ultimate aim of developing an all Wales document and policy.

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