



UNIVERSITY OF
SURREY

**A Values-Based Approach to End of Life Care
Planning for Young People with Learning
Disabilities & their Families & Friends**

The ADVANCE Toolkit

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1. Introduction

The delivery of good end of life care for young people with learning disabilities is an important goal for care-givers. Every day, care-givers in hospital, hospice and learning disabilities services work with young people and their families and friends who would benefit from time and space to consider end of life care options. Whereas much is now known about end of life care generally and what needs to be in place for a good end of life experience, there has been less attention to End of Life Care Planning (EoLCP) with young people with learning disabilities and their families and friends. What we do know is that people with learning disabilities experience health inequalities that extend to palliative and end of life care (see http://cdn.basw.co.uk/upload/basw_75155-8.pdf)

A useful working definition of End of Life Care Planning as it is addressed in this project, is:

Conversations whereby young people with learning disabilities and, where appropriate their families and friends, are provided with opportunities to share, have documented and disseminate their wishes regarding their preferred care and treatment as they move towards the end of life.

The process of End of Life Care Planning involves conversations with people with a range of different abilities, for example:

- Conversations with care-recipients who have capacity and their families, that is, with those who are able to communicate their wishes regarding end of life care. These conversations involve doing everything possible to ensure the wishes of young people are invited and respected, particularly for when they may lose capacity. If they retain capacity, they will be in a position to change their decisions so long as they are able to communicate.
- Conversations with parents or other nominated people who know a young person with compromised capacity well and where the young person is unable to express her/his views. When young people are considered not to have capacity, this is likely to involve 'best interests' decision-making.

All of these conversations involve documentation of wishes and ensuring the young person's wishes are honoured whenever possible. In terms of the types of decisions involved in End of Life Care Planning, there are two broad areas for consideration:

- **Personalised care options** – This would involve: **Who** would I like to be with me towards the end of life? **Where** would I like to be if this is possible – my preferred place of dying? **What** would I like around me, for example, music, special items? **How** would I like to be cared for? and **When** would I like the particular options?
- **Medical intervention options** – What pain relief options are there? Treatment for sickness? Resuscitation to be attempted? Resuscitation to be declined? What other medical interventions could be provided or withheld?

End of Life Care Planning is a **values-based activity** [See **Section 5** of this Toolkit] and requires knowledge, skills and ethical competence to do it well. This is particularly important in areas of care where people have limited ability to express their wishes and where they are in between childhood and adulthood (aged between 16 and 25). Their end of life care needs are often more complex and more challenging to meet, but when we get them right it makes a positive difference to the young person and her/his family.

People with learning disabilities do not always receive good end of life care (see, for example, <https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf>). They are too often misunderstood, disrespected and disregarded.

The term 'learning disability' encompasses a wide variety of different levels of functioning and disability and is a concept which the World Health Organisation treats as multi-dimensional and as resulting from a dynamic interaction of health condition with complex environmental and social factors. Internationally this is referred to as 'intellectual disabilities'. Those we worked with on this project preferred the term 'learning disabilities'.

People with learning disabilities are often disadvantaged by being assumed to be a group with similar needs and preferences and lacking diversity (see, for example, Blair 2016, Blair 2017). Such assumptions can impact negatively on communication with young people and their families and friends about end of life care. Young people with the most severe and profound problems are least likely to get the chance to make their wishes understood. More on the topic of learning disabilities in Section 3 below.

End of Life Care Planning can take place at any time but typically takes place when a person has a life-limiting condition. Whereas it usually occurs before the individual loses capacity, in many cases, people with more severe learning disabilities have never had capacity and are unlikely to develop to the stage where they do. In other situations, it can be difficult to assess whether or not a young person with some limited ability to communicate has the capacity to understand and participate in such decisions.

These challenges illustrate why working with families and friends, informal care-givers - indeed anyone who knows the individual well - is so important when discussing end of life wishes for people who have learning disabilities. Young people with learning disabilities, especially those whose condition has left them socially isolated, tend to rely to some extent on their parents or guardians for decision-making and emotional support. This makes End of Life Care Planning as much about working with whole families and friends as about working with people with learning difficulties themselves. So long of course that we have the agreement of the young person if they are able to give consent. Finding ways to support and protect family members as they deal with issues of palliative care is another respect in which End of Life Care Planning raises additional challenges not faced in other contexts.

Young people with learning disabilities are equally deserving of good end of life care as anybody else. A good understanding of their wishes is essential if we are to ensure

they, like all others, live as well as possible until they die and have the manner of death they choose as far as possible.

This Toolkit is designed for care-givers – primarily nurses, social workers or care assistants - who work with young people with learning disabilities who have a life-limiting condition and their families and friends. The Toolkit aims to enable care-givers to develop knowledge and to practise communication skills so they feel more confident and competent to work with young people and their families and friends as they plan end of life care.

2. What is End of Life Care Planning?

End of Life Care Planning is a wide-ranging process and can include Advance Care Planning, End of life Statements and End of life decisions. On a more everyday level, we argue that End of Life Care Planning involves structured conversations between care-givers and care-recipients with a view to ensuring that the latter's wishes about end of life care are invited and respected as far as possible. Our preference throughout this Toolkit is to define End of Life Care Planning (EoLCP) as stated above:

Conversations whereby young people with learning disabilities and, where appropriate their families and friends, are provided with opportunities to share, have documented and disseminate their wishes regarding their preferred care and treatment as they move towards the end of life.

Other related initiatives such as **Advance Care Planning** have been receiving increasing attention since the 1990's. It is now an important part of the Department of Health's *End of Life Care Strategy* (<https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>) published in 2008. The Strategy recognises that a key part of living well is dying well. Having a 'good death' can, however, mean different things to different people. Hence the importance of engaging with each unique individual and, where appropriate, his or her family and friends. The aim is to discover what his/her wishes are - or might have been - and how best to honour each individual person's unique set of beliefs, wishes and views.

There remain different views as to the meaning of Advance Care Planning (ACP). Some may see the process merely as an opportunity to complete an end of life directive or do-not-resuscitate order. Whereas other more positive approaches treat ACP as an ongoing, iterative process (Ahluwalia et al (2015)). This process is, at its core, an interpersonal one and is dependent on the development of respectful relationships. It emphasises the need, for example, to find meaningful and appropriate ways to discuss ACP with care-recipients and their families and friends in order to accurately gauge their wishes without leading them down a particular path or causing unnecessary upset.

Other terms related to End of Life Care Planning are **End of life Statements** and End of Life Decisions. Information from NHS Choices (see http://www.nhs.uk/Planners/end-of-life-care/Pages/end_of_life-statement.aspx#What) defines an End of life Statement as:

[...] a written statement that sets down your preferences, wishes, beliefs and values regarding your future care. The aim is to provide a guide to anyone who might have to make decisions in your best interest if you have lost the capacity to make decisions or to communicate them.

Such statements can relate to a person's religious or spiritual beliefs, to their preferred place of care – where this is possible - and to preferences about personal care and other practical matters (for example, who would look after a pet). [See also **Advance Statements** <http://www.nhs.uk/Planners/end-of-life-care/Pages/advance-statement.aspx> & also information relating to the Mental Capacity Act – see <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mental-capacity.aspx> relevant to those aged 16 and over)

An **Advance Decision**, on the other hand, which is also known as a 'living will' or 'end of life decision to refuse treatment' enables a person to refuse medical interventions in end of life and has legal status (See . <http://www.nhs.uk/Planners/end-of-life-care/Pages/advance-decision-to-refuse-treatment.aspx>). See Health Education England eLearning Resource - <https://www.e-lfh.org.uk/programmes/end-of-life-care/>

Before we discuss specific issues relating to End of Life Care Planning with young people with learning disabilities, we invite you to reflect on your understanding:

Activity 1 – Terminology in End of Life Care Planning – True or false? [5 minutes]

- Advance Care Planning is a recent innovation – true/false?
- End of Life Care Planning is about helping people to live as well as possible until they die – true/false
- It should be assumed that young people have similar wishes regarding their end of life care – true/false?
- An End of life Statement is a written account of the care someone would like in the future – true/false
- An Advance Decision regarding refusal of treatment has legal force – true/false?

FEEDBACK

Advance care planning is relatively recent with more activity since the 1990's. The intention of End of Life Care Planning is to enable people to have a death of their choosing as far as possible. It should not be assumed that people have similar wishes, therefore, good communication with young people and their families and friends is essential. An End of life Statement is a written account of a future person's care preferences. An Advance Decision represents a legal right to refuse care for those who have capacity.

Making a living will or an end of life directive to refuse specific treatments are now part of the broader range of choices discussed under the umbrella of End of life Care Planning. A more inclusive and integrated approach emphasises making people

aware of a range of options available to them, facilitating open discussion of these options with their families and ensuring that their subsequent wishes are taken into account. This process honours the full spectrum of views and beliefs that reflect who the individual is as a person and are opting to refer to this as End of Life Care Planning. One of our Advisory Group members described it as follows:

A formal care plan that includes details about the child or young person's condition, decisions made with them and their parents or carers (for example about managing symptoms), and their wishes and ambitions. This plan is a core element of their palliative care.

Overall, then, the key features of the process of End of Life Care Planning include: **capacity** (so the person can understand information and make decisions on the basis of it); **voluntariness** (the person has to want to engage in conversation about future care); **gaining clarity** about a person's wishes; **communication** of those wishes; and having a **strategy for informing others** of those wishes should the person lose capacity.

What is not highlighted here – and which is very important when we consider young people with learning disabilities – is **the role of their family and other loved ones**. Before moving to the next section of the Toolkit we invite you to complete the following Activity. Readers of this Toolkit may have given some thought as to what it means for them to die well and what arrangements they would like to have in place for this to happen.

Activity 2 provides the opportunity for you to reflect on this for yourself before we progress to other sections of this learning resource.

Activity 2 – My End of Life Care Wishes (30 minutes)

Talk with a trusted friend, family member or colleague about your end of life care wishes and make some notes:

- What are the most important things you need to sort out before you come to the end of your life?
- Where would you like to die if it is possible to choose?
- How would you like to spend your final days and hours?
- What might you be afraid of as you approach the end of life?
- What would provide most comfort to you in your final hours?
- Who would you like to be alongside you during your final hours?

FEEDBACK

Those we talked with told us it was important to them to put their 'affairs in order'. Some said they intended to have, in addition to a will, a letter of wishes so some of their treasured positions could go to people they loved. Some people said they would prefer to be in a hospice at the end of life and some others said they would rather be at home. However, the latter depended on what they felt their family would be able to bear. Some people will have clear ideas about the environment within which they would like to end their life whilst for others the people around them were the most important consideration. In terms of fears, most people cited 'pain' and 'suffering' as the experiences they were most afraid of and also uncertainty as to what follows from death. Comfort could come from pain relief and other forms of symptom control but also in having a loving presence at their side.

We turn next to the nature of learning disabilities

3. What's Special about Young People with Learning Disabilities?

Despite the development of palliative and end of life care and increased recognition of the value of End of Life Care Planning, some groups are still less likely to have the opportunity to plan for a “good death” (Oliviere and Monroe, 2004). Some of the most disadvantaged individuals are young people with learning disabilities.

So what does it mean to have a ‘learning’ disability? The third activity invites you to check your understanding of this.

Activity 3 – What are learning disabilities?

Using a computer, access the two web-sites and write down your answers to the questions below - <http://www.learningdisability.info/about-us> & <https://www.mencap.org.uk/learning-disability-explained>

1. A learning disability is....
2. What is the significance of age in relation to people with learning disabilities?
3. What is the difference amongst mild, moderate and severe learning disabilities?

FEEDBACK

From your reading you will have learnt that ‘learning disability’ refers to a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.’ It is also the case that people with a learning disability may take longer to learn and need support to gain new skills, to understand information and to relate to other people.

You will also have come to appreciate that the label ‘learning disability’ covers a wide range of abilities. Some people with mild learning disabilities can be independent and will be able to engage fully in education, social life and work. They are able to communicate well and look after themselves, albeit taking a little longer to learn new skills. Others may have moderate learning disabilities and may require some care and support whilst others will require a lot of support and this may also include for physical disabilities which can be mild, moderate or severe. This covers a wide range of abilities and levels of dependence. It should always be assumed that young people who have a learning disability are aware of what goes on around them. However their ability to understand and communicate this will vary, as well as having difficulties in expressing themselves in relation to their hopes and wishes and symptoms. This is why it is important to work with their families and friends so that we can provide meaningful end of life care plans.

The significance of age in relation to people described as learning disabled is that development is usually curtailed at a stage of development and there is not the usual progression over time. This needs to be borne in mind particularly as the young person is transitioning from ‘child’ to ‘young adult’ with assessment of their abilities throughout this period.

4. End of Life Care Planning with Young People with Learning Disabilities and their Families and Friends

End of Life Care Planning encourages people to make important decisions regarding their end of life care and treatment. Some people with learning disabilities may have less ability to understand the relevant issues and to make end of life decisions. They may also have difficulty communicating or expressing themselves in ways that those who know them less well are able to understand. This places ever more importance on the ability of care-givers to raise and discuss sensitive issues around planning for end of life care with the person herself, her family members or other informal carers.

In End of Life Care Planning the care-giver is also encouraged to work with family care-givers to help the person express their wishes and to participate in the decision making process to the right extent for that person. (See My Adult – Still My Child website - <http://myadultstillmychild.co.uk/>)

End of Life Care Planning is an ongoing, iterative process and time and space need to be made to do it well. This is even more the case when it comes to children and young people with learning disabilities. Getting to know the young person's abilities and the nature of their relationships with family and friends is essential. We invite you next to consider the question areas that apply to End of Life Care Planning with Young People with learning disabilities.

Activity 4 – Question areas relating to End of Life Care Planning? (20 minutes)

Think of someone you know who works with or has a young family member with a learning disability. If you were asked to construct an End of Life Care Plan with the person with learning disabilities, what questions would you ask?

FEEDBACK

At a recent workshop at the June 2017 'Building Our Community - Kent Surrey & Sussex Learning Disability Community of Practice Conference' we invited participants to identify elements of a Care Plan for young people with learning disabilities. They suggested the following questions:

- Why are we having this conversation?
- What does this person know?
- What is going to happen?
- Does the person want family involved?
- What don't they want?
- What helps when sad?
- What matters to you?
- Who do you want with you?

It is important to have adequate time and space to have a meaningful conversation.

5. Underpinning values – The ADVANCE Framework

End of Life Care Planning gives people a way of ensuring that their voice will be heard and their choices honoured – where possible - including when they are no longer able to make such choices or have no voice to express them. This often means having a say in how, where and when they will die. It is therefore a key means of enabling people with learning disabilities to continue to exercise as much autonomy as possible.

An End of Life Care Planning conversation has additional benefits in ensuring the young person is aware of the options available to them. The process creates an opportunity to discuss the person's needs and wishes with family and other care-givers also IF the person with learning disabilities is happy with this.

In some cases, a trusted individual may be appointed to represent their wishes in the future, be it informally or by granting them lasting power of attorney. The existence of an End of life Care Plan can also give family members the consolation of knowing that the difficult choices made about their care were in accordance with their loved one's wishes.

There is the further benefit of informing a range of professionals involved with the young person, who may not have had prior opportunity to discuss care and treatment options with the person or each other, to have access to a record of the person's stated preferences and values. This allows for greater continuity of care, ensuring that the care delivered is consistent and appropriate no matter who is providing it.

From what you've read so far, we now invite you to consider a Framework of Values that can be applied to End of Life Care Planning with young people with learning disabilities.

We have incorporated insights from the Health Education England eLearning materials 'End of Life Care for All' (see <https://www.e-lfh.org.uk/programmes/end-of-life-care/>).

Please now turn to the **values-based ADVANCE Framework** on the next page.

The ADVANCE Framework

A Values-Based Approach to End of life Care Planning (EoLCP) for Young People with Learning Disabilities

Assumptions – Avoid making assumptions regarding the abilities and wishes of care-recipients and families & friends. Care-givers need to be well informed about the person's health status, capacity and family and support network. What this means in practice is that care-givers need to check out the young person's understanding of their health status and of the most appropriate means to communicate with him/her.

Dignity – Respect the worth of each individual in the care context. There needs to be open-mindedness to, and respect for, diversity. This is not only in terms of disability but also related to race, class, gender and sexual orientation. In practice, this involves engaging with the young person first and taking time to get to know him/her before moving to finding out their end of life preferences.

Vulnerability – Be sensitive to people's vulnerability towards the end of life. This includes young people, families, friends and professional care-givers. Less experienced care-givers will also need support to enable End of Life Care Planning. This also involves advocacy and awareness of safeguarding responsibilities.

Autonomy – Strive to maximise information-giving and understanding of all regarding end of life care options. A HEE e-learning resource states that end of life care planning 'is a [person] centred dialogue carried out and reviewed over a period of time. The content of any discussion should be determined by the [person] in question, they may be encouraged to include an informal carer, relative or significant other in the discussion if this is their wish.' Advocacy is also an important aspect of supporting autonomy.

Non-Discriminatory practice – Respect the rights to care of a person with learning disabilities. As the HEE e-learning resource states: 'Professional care-givers should be open to any discussion which may be instigated by the [person], even if it goes against their own initial opinions'. Open-mindedness on the part of the care-giver is required.

Commitment – Care-givers require ethical qualities such as kindness, patience, justice, honesty and integrity also. As the HEE resource reminds us: 'They need to be able to fully provide the young person with relevant information about the range of options that are likely to be available to them in the future should their condition worsen.'

Environment of care – Ensure this is safe, peaceful, private and as life-affirming as possible. The HEE resource highlights the importance of 'time and setting'. The conversation 'should take place in private, be allowed adequate time, with the decision of who else to have present' left to the individual.

6. Good Communication & End of Life Care Planning

Good communication in End of Life Care Planning is essential. The values in the ADVANCE framework remind of the importance of: not making assumptions; respect for human dignity; the presence of vulnerability of young person, family and care-giver; respect for autonomy; non-discriminatory practice; the importance of genuine commitment to ethical care; and to the development of an environment of care that is safe, peaceful and private.

Preconditions for End of Life Care Planning communication, as discussed earlier, include capacity, voluntariness, clarity in communication and a strategy to inform all who need to know what the young person's wishes are. Information is required by the young person's family (with their consent, where possible) and care-givers so all know what they need to know to ensure as far as possible that the end of life care plan is implemented. It is acknowledged that such communication can be challenging and this is the topic of the next activity which we invite you to complete.

Activity 5 – Barriers to End of Life Care Planning Conversations? (15 minutes)

What are some of the barriers to having conversations about End of Life Care Planning with a young person with learning disabilities from the perspectives of:

- a) The young person with a learning disability?
- b) The formal care-givers?
- c) Family members?

FEEDBACK

You may have considered some of the barriers that previous workshop participants considered? Do add additional barriers to the table if you've come across others.

Young person	Care-givers	Family members
Wishing to please staff. Not having the vocabulary to talk about wishes and dying. Feeling fearful of the future. Not understanding what is being said. Wanting to be a good patient. Feeling uncomfortable with the expression of feelings.	Not wanting to cause distress or upset. Feeling unskilled. Not knowing where to start. Wanting to protect the young person and the family. Feeling that 'it's not my job' and 'passing the buck'. Lack of time. Feeling uncomfortable with expressing feelings.	Difficulty in accepting that young person is dying. Wanting to protect young person by not discussing prognosis. Having different views within the family as to what is best for the young person. Believing there is stigma relating to hospice care. Not feeling about to talk about dying, loss and grief.

From Activity 5 we have identified many barriers to having conversations about End of Life Care Planning and dying and the barriers are understandable as conversations such as these involve sensitive communication. The barriers that health and social care professionals use have been referred to as “distancing tactics” so that end of life care conversations are avoided, the topic changed or physical care is prioritised over psychosocial care and avoided altogether (Maguire, 1999).

Activity 6 – ‘Janine’s’ End of Life Care – Challenges & Opportunities [25 minutes]

Before you watch the video clip, write down your answers to these questions:

- Who should be involved in end of life conversations?
- When should the end of life conversations take place? Is there a ‘right time’?
- Should these conversations be an ongoing part of end of life care?
- How should care-givers start an end of life conversation? How do they know the young person is dying?
- What role does ‘trust’ play in an end of life conversation?
- What would it mean for an end of life conversation to ‘go well’?

- Now watch the video clip which you can download from the link on the project section of the ICE Observatory website - <https://www.surrey.ac.uk/international-care-ethics-observatory/research> - and compare your responses to the questions with her experience of working with ‘Janine’ and her family.

FEEDBACK

Rosie, the care-giver in the video, talks honestly and openly about the challenges and opportunities of working with ‘Janine’ and her family. She highlights the importance of bringing together key professionals with the family so that the needs of all can be considered, including those of Janine’s sister. You also heard Rosie talk of the importance of taking time to build relationships, of developing trust and of providing continuity. The end of life care situation became evident when the young person was becoming very ill and having very frequent admissions to hospital with breathing difficulties and visible discomfort. She also had undergone a number of resuscitation events. Was Rosie’s experience similar to experiences you have had working with young people with learning disabilities and their families? What additional guidance would you give to people who have less experience in end of life care?

Conversations about End of Life Care Planning should start as early as is possible and should be on-going and documented in the care plan. It is an important principle that family members are involved in end of life conversations as well as the

young person with learning disabilities and that wishes of the individual and the family are balanced, where possible, with all being heard but agreeing that the young person's interests are paramount.

Key Strategies for an End of Life Care Planning Conversation are below:

Appropriate setting	Allow time. Discussion held in person and not by telephone. Ensure privacy and avoid interruptions ensuring the comfort of both the individual and the family member/s and their dignity. The person may wish to be alone or accompanied.
Introduce the discussion	Starting conversations with the person and or family member about their wishes and choices for end of life care require sensitive communication. Use language appropriate to the situation and avoid using euphemisms. Appropriate tools and resources to aid communication may be needed according to the severity of the individual's learning disability.
Find out what they understand about the situation	Explore understanding of the situation and what is happening. Explore this where possible using open questions such as "tell me about what has been happening"? What concerns worries do they have? What is worrying them most? It is important to ask and not to make assumptions.
Explore and encourage the expression of feelings	Use facilitative skills such as listening to verbal and non-verbal communication, use educated guesses, be empathetic, for example, "This must be really hard for you", "How are you feeling today?" It is important that the young person with learning disabilities feels able to communicate his/her worries and sadness and that these feelings are facilitated in a trusting relationship.
Find out what they expect	What expectations do young person and family have? What are they hoping for and expecting to see in the future? For example, "Tell me what you would like to happen?"
Provide information, if necessary	Give as much or as little information as they wish to have in an appropriate form and in relation to capacity and ability. Avoid using euphemisms and medical jargon. Use chunking and checking when giving small amounts of information and then checking back to see if the information has been understood. Use appropriate tools and resources to aid communication and understanding.
Summarise the conversation and document in the care plan	Conversations about end of life care planning and care and choices should be documented in the personalised care and support plan. Every young person should have an agreed transfer plan to adult services in both acute and community services.
Good support for staff & family is necessary following the death.	Access to clinical supervision and to receive good support is essential to prevent burnout. Staff should also have support following the death of the individual as should family care-givers.

7. Conclusions

The ADVANCE Toolkit is intended to enable care-givers to reflect on the topic of End of Life Care Planning with young people with learning disabilities and their families and friends.

Death and dying can be challenging topic areas and are too often conversation stoppers. We hope this Toolkit will serve as a conversation starter and that you will gain in confidence and competence to initiate and sustain important conversations about end of life care.

We hope also that these conversations will enable young people with learning disabilities and their families and friends to feel listened to and that they will feel reassured that the plan in place will be honoured as far as possible.

To develop the necessary communication skills it is recommended that you talk opportunities to practice skills in follow-up workshops or in role-play situations in your own practice area. We hope that you will use this resource to develop the knowledge and skills of people in your team so that ethical and competent End of Life Care Planning conversations can take place across services keeping the young person with learning disabilities at the centre.

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Together for Short Lives, a UK charity for children and young people with life limiting conditions. [Visit website](#)

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Additional Resources

See Health Education England eLearning Resource - <https://www.e-lfh.org.uk/programmes/end-of-life-care/>

Regarding **palliative care resources for people with learning disabilities** we recommend you access this website - <http://www.pcpld.org/links-and-resources/>"

See also the ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) website - <http://www.respectprocess.org.uk/faqs.php> - this is a helpful resource and is intended to become the national approach to ACP.