

A Guide for those who have a life limiting illness.



For a specialist, professional advice.
Help when you need it most.....

I hope you find this guide to be
of assistance.

CHRIS BERRY

A guide for those who have a life limiting illness

Coming to terms with the prospect of the end of life is never easy.

It can feel at times that there are a bewildering number of issues to address.

We hope this guide can in a small way be of help.

It's good to talk.

Whatever our age whether young, middle aged or older this is a conversation which we can all enter into whether with friends or family.

Finding the right place and time are never easy and despite your own needs try not to rush others into talking about such matters. Try to bear in mind those who you love and care for are equally frightened and perhaps scared.

Initially if you are facing a life limiting illness you may find it easier to talk to a suitable professional to help formulate your own views. Your Doctor and Consultant are always willing to help and talk with you. A suitable Solicitor of your choice will be able to address appropriate issues. These and many others will be able to help you address any worries and concerns you may have.

Why talk about it?

Everyone is different and has differing needs and requirements.

Talking about the illness helps in reducing anxiety for all parties concerned. Everyone can gain knowledge as to what to expect and how to respond to the illness and its consequences.

By talking this in itself helps towards informed decision making by all parties. What are peoples wishes, sometimes these may not be immediately clear. However by talking this may well help to find a path through the maze of issues.

Taking control and peace of mind. Starting talking and taking the first steps in decision making breeds confidence for all parties and this encourages further steps to be taken and decisions to be made. This then provides assurance and knowing you are taking control of the situation. This in its own right starts bringing peace of mind.

No one wishes to be a burden and equally friends and family need to know your wishes and desires. Such knowledge breeds confidence and saves unnecessary distress for all concerned.

Once the mists of anxiety starts clearing then a sense of purpose& freedom and a will to get on with living can then be achieved.

What am I going to be talking about & where do I start?

If you have a life limiting illness it may well be a good idea to go along to your Doctor or Consultant together with your partner close relative or friend to chat about your illness so that an idea can be gained as to what to expect as things progress.

Sometimes it can feel like a blizzard of words is being spoken. Often the discussion can feel disjointed and you are catching only snatches of the conversation and partial understanding being gained. Do not worry and do not panic, the person with you will be able to help in part discussing the issues and it is important to appreciate your Doctors door is always open to go through matters.

Talking money. Managing finances in the future is an important consideration. Are your finances in order?

Sometimes, if you have a partner, your partner may not have been involved in looking after the family finances. Now is the time to help them to learn to deal with day to day essentials, paying bills, direct debits, utilising a bank account.

You need to consider and discuss what income is likely to be received and what outgoings have to be paid

Have you made your Will? Do you want to review your will?

Have you made a Lasting Power of Attorney? It is important to appoint someone who you trust to deal with your affairs should you not be able to deal with or do not wish to deal with same.

We will talk a little later about the importance of having a will and a Lasting Power of Attorney

Where to live. It may be that more help will be needed and this may impact on the household arrangements. Try and give this some thought, having regards to living arrangements.

Type of Care. Quite often this is one area where people hold particular wishes and preferences about how to be cared for. It is so important to talk with your partner, or family and friends as to those wishes and preferences. It is important to get in place legal formalities to ensure those wishes and preferences are carried out. By appointing an Attorney you are vesting such power in a person or persons of your choice who you know will carry out your instructions to the best of their ability

Emergencies. It is quite natural to try not to think about what will happen to a person if an emergency arises. However it is good to talk and see what alternative plans there might be to meet such occasions.

Funerals. Such discussions in today's society are quite open and commonly held between parties. Indeed it can lead to some eye opening thoughts and banter between parties and on occasions cast some light on a parties past which had had been long lost or forgotten. Making a funeral plan and having regards to where and how you wish a ceremony to take place are all important issues.

I really do not wish to talk about such matters.

Well that is an option but what are the possible consequences?

Your affairs may be referred to the Court of Protection because a power of attorney could not be authorised. This is expensive, a needless drain on your assets, unnecessary delays are encountered which may have an impact upon the nature of your care and someone not of your choice could be appointed to look after your affairs and make decisions on your behalf which never in a month of Sundays would you have allowed anywhere near your personal matters.

Decided not to make a will? This is not the wisest of decisions and that can lead to relatives with whom you have had little or no contact to benefit and equally those who you cared for receiving perhaps a portion of your estate which could lead to financial hardship for such parties.

Fundamental as those issues are more importantly you are denying not just yourself but those you care for taking the moment to say thank you.

Remember it's good to talk.

Making a Lasting Power of Attorney

At such times it is always sensible to consider how you will manage your affairs in the future should you be unable to deal with them.

So there are a number of practical steps you can take to prepare for the future.

In the first instance you can be getting your affairs in order by making a Property and Financial Lasting Power of Attorney. When a person (the Donor) has capacity they can give someone else the power to manage their financial affairs. Sadly none of us can predict when we are likely to need a Lasting Power of Attorney so it is important to make such an appointment when a person has the capacity to do so.

A Solicitor can prepare a Property and Financial Lasting Power of Attorney and you will be some way being safe in the knowledge that your financial affairs are being looked after by those you have appointed.

Remember if the Donor leaves it too late & does not have the capacity to make a Lasting Power of Attorney then friends and relatives will need to approach the Office of the Public Guardian for the appointment of a Deputy to deal with a persons financial affairs. Unfortunately this can prove to be very costly and time consuming.

It is a good idea to make a Property & Financial Lasting Power of Attorney whilst you have capacity.

In the second instance and for the same reasons we would also strongly recommend you have a Health & Care Lasting Power of Attorney prepared.

A Health & Care LPA can be made to give your attorney the right to make personal welfare and medical treatment decisions on your behalf. This is particularly relevant where decisions as to what provision of care is required suitable for you and where such care is to be provided. Equally if you wish you can vest power in your Attorney to give or refuse consent to life sustaining treatment on your behalf.

Remember a LPA whether Property & Financial Affairs or Health & Care gives you the opportunity of appointing an **Attorney of your choice** and who you wish to deal with your affairs. This then avoids the possibility of others, who you may deem inappropriate, applying to the Court to be appointed to deal with your affairs.

Lasting Powers of Attorney are essential for everybody regardless of age.

Think carefully about the person or persons who you appoint as your Attorney. Not everyone is naturally suitable to fulfil that role. If you feel there is no one suitable then you can always appoint a Solicitor to deal with such matters.

Making a Will

Who should make a will?

If you care about what happens to your property after you die, you should make a will. Without one, the state directs who inherits, so your friends, favourite charities and relatives may get nothing.

It is particularly important to make a will if you are not married or are not in a registered civil partnership (a legal arrangement that gives same-sex partners the same status as a married couple). This is because the law does not automatically recognise cohabitants (partners who live together) as having the same rights as husbands, wives and civil partners. As a result, even if you've lived together for many years, your cohabitant may be left with nothing if you have not made a will.

A will is also vital if you have children or dependants. Without a will there could be uncertainty about who will look after or provide for them if you die.

Once you have had a will drawn up, some changes to your circumstances – for example, marriage, civil partnership, separation, divorce or if your civil partnership is dissolved (legally ended) – can make all or part of that will invalid or inadequate. This means that you must review your will regularly, to reflect any major life changes. A solicitor can tell you what changes may be necessary to update your will.

Using a solicitor

Although it is possible to write a will without a solicitor's help, this is generally not advisable as there are various legal formalities you need to follow to make sure that your will is valid. Without the help of an expert, there's a real risk you could make a mistake, which could cause problems for your family and friends after your death.

What your solicitor will need to know

Once you have appointed a solicitor, they will need the following details from you.

What you own

Details of everything you own, including property, cars, personal valuables, stocks and shares, bank accounts, insurance policies, any businesses you own, and pensions.

Who gets what?

Who do you want to leave these assets to? How do you want to divide your property between your loved ones, friends or charities?

Family and other beneficiaries

Details of your family and status. Are you divorced or has your civil partnership been dissolved? Have you remarried or entered into a new civil partnership? Or are you living with someone without being married to them or being their civil partner? Do you have any children or any other dependants? Anyone who depends on you financially can ask a court to review your will if they feel you have not provided properly for them. If you give your solicitor relevant details, they can tell you about any legal pitfalls.

Guardians

If you have any children who may still be under 18 when you die, you may need to name someone as their legal guardian.

Other wishes

Do you have any particular wishes for your funeral? Do you want to be buried or cremated? Are there any other instructions? For example, if you want to be an organ donor this can be included in your will. However, it is also a good idea to record your wishes on the organ-donor register, or to carry an organ-donor card.

Executors of your will

You must also name the people you want to appoint as 'executors' of your will – the people who carry out the administration of your will after your death. These could be friends or family members, or a professional such as your solicitor. Ideally, you should choose someone who is familiar with financial matters. Make sure you ask your executors whether they are happy to take on this duty as there are long-term responsibilities involved, particularly if you include a trust in your will.

Signing the will

Once the will has been drawn up it is not effective until it has been signed. There are several rules affecting the signature process which, if not followed correctly, will make your will invalid. For example, witnesses and their husbands, wives or civil partners cannot benefit under the will. Many people use staff at their solicitor's office to act as their witnesses to avoid this problem.

Where to keep the will

It is important to keep your will in a safe place and tell your executors, a close friend or relative where it is. People often ask their solicitor to store their wills for them. Most solicitors will do this for free, but sometimes there is a small fee.

Keeping your will up to date

You should review your will at least every year and after any major life change such as getting separated, married or divorced, having a child or moving house. It is best to deal with any major changes by getting a new will drawn up.

Costs

Charges for drawing up a will can vary between solicitors.

They also depend on:

- the experience and knowledge of the solicitor; and
- how complicated your will may be.

Before you decide who to use, check with a few solicitors to find out how much they charge. But remember that cost should not be the only consideration. It is equally important to find a solicitor who is approachable and whose advice you understand.

Remember

By making a Will:

- You name your Executors, the people who deal with all the paperwork and procedures.
- You decide who should inherit your estate.
- You can arrange special bequests to specific people.
- You can appoint a guardian if you leave any young children.
- You can decide what type of funeral you want.

Without a valid Will the Law is in control and what it says might not be a reflection of your wishes. For example:

- If you are married, your husband or wife does not automatically inherit the whole of your estate.
- If you and your partner live together but aren't married the Law favours relatives over a non-married partner.
- Friends and charities do not benefit.

Does your will need updating?

If you already have a will in place and your circumstances have changed you may need to update your existing will to reflect this. Divorce, remarriage, the birth of a child and the dissolution of a civil partnership are just a few examples of events that may cause you to reconsider your will.

Does your Existing Will Exclude or make limited provision for dependents or family?

In such circumstances it is going to be very important that you have a will drawn together with a supporting statement drawn to seek to satisfy the provisions of a recent Court of Appeal case.

Where members of the family or dependants or people who deem themselves dependants are either excluded from your will provision or limited provision furnished to them. In such case it is open to such parties to make an application to the Court to consider a claim against your Estate for failure to provide any or adequate/reasonable Financial Provision for such person.

You need to not only have a will but also have a supporting statement setting out the reasons for your wishes and having due consideration of all parties circumstances so as to seek to provide a rebuttal to any claim based on the failure to provide any or adequate provision is sustainable. Such statement and consideration can then be noted with your will and if necessary your Executors may then utilise same for any claim against the Estate. Failure to do is likely to weaken the Estate's position in rebutting any challenge.

You need to be aware that any such claims can be extremely costly against the Estate and possibly run into tens of thousands of pounds to deal with such challenges. We mention this so that you are aware of the implications. If you have a supporting statement dealing with the necessary issues to be considered then this will go some significant way to either deterring any prospective claimant from raising a challenge to your estate or providing a form of rebuttal which the Court would have to carefully consider.

Even in circumstances where a party, partner or prospective partner has made declarations stating they have no wish to benefit from your Estate it is still very important to provide a supporting statement as to the circumstances and reasons why no provision is being made. Clearly there is nothing to stop such a party making a claim against your Estate once you have passed away.

Advance decisions and advance statements ensure that your wishes are taken into account in the future.

WHAT ARE ADVANCE DECISIONS & ADVANCE STATEMENTS?

Advance decisions and advance statements are just one aspect of planning ahead. For example, you can decide if you would like to choose someone to manage your finances on your behalf if you are unable to in the future, or make decisions relating to your health and welfare.

Other things you may wish to think about are putting your finances in order and getting a will, or updating any previous will. This allows you to state who you want to inherit your estate.

What is an advance decision?

An advance decision gives you the opportunity to make decisions now about specific treatments that you may not want to receive in the future. The purpose is to ensure that, if you are not [able to make decisions](#) about treatment or consent yourself in the future, you are not forced to receive treatment that you would not want.

Treatment that can be refused includes life-sustaining treatment. For example, some people may write an advance decision to refuse a blood transfusion for religious or spiritual reasons, even if this will hasten their own death.

Advance decisions are legally binding as long as they fulfil certain requirements, and this means that they must be followed by doctors and other [medical professionals](#). This factsheet details these requirements so that you can ensure that any advance decision you make will be valid.

What is an advance statement?

Advance statements are similar to advance decisions, but they are not the same thing. It is important to note that you can make both an advance statement and an advance decision.

An advance statement can be made verbally, or you can choose to write it down, which can be better because it is a permanent record. An advance statement gives you the chance to make more general statements about your wishes and views for the future, whereas an advance decision is about refusing certain treatments. Often an advance statement is referred to as a 'statement of wishes and care preferences'.

You could use an advance statement to express your wishes on future [care options](#), such as where you wish to live, or the type of care and support you wish to receive.

An advance statement can also be used to express other wishes and preferences not directly related to care. Examples include stating food preferences, such as being vegetarian or not eating seafood, or your preference for having a bath over a shower. If you have particular religious or spiritual views, an advance statement provides an opportunity to ensure that any relevant values that you hold are taken into account by the people who make decisions for you.

You could also include a list of people, such as your partner, family or friends, who you wish to be consulted by health and social care professionals who are making decisions about your care.

Advance statements are not legally binding.

Why should I consider making an advance decision or advance statement?

There are a number of reasons why you may wish to make an advance decision or advance statement:

- It can be reassuring to know that, if you are [unable to make a decision](#) about your care in the future, you will not be given treatment that you do not want.
- They are a way of ensuring that your views and wishes are taken into account in the future.
- Creating an advance decision and/or advance statement can help to start conversations with doctors and nurses that you may not otherwise start.
- They can also help to prompt discussions with your family about your wishes, and making an advance decision and/or statement can take the burden away from your family, who otherwise may be asked to make these decisions for you.

Will my doctor have to follow my advance statement?

An advance statement – unlike an advance decision – is not legally binding, so doctors and medical professionals do not have to follow it. However, it should still be taken into account by health and social care professionals when making decisions about care and treatment.

Will my doctor have to follow my advance decision?

All medical professionals, including doctors, will have to follow your advance decision. However, this is only when your advance decision is 'valid' and also 'applicable'.

- **Valid** – In order to be valid, an advance decision must have been made at a time when you were able to make this decision. This is referred to as having mental capacity.
- **Applicable** – In order for the advance decision to be applicable, the wording has to be specific and relevant to the medical circumstances. If the wording is vague or there is a concern that it does not refer to medical conditions and/or practices that you are actually experiencing, then the advance decision may not influence the doctors' decisions at all.

The advance decision must also:

- be clear and unambiguous
- have been made when you were over the age of 18, and fully informed about the consequences of refusal of treatment, including the fact that it may hasten death
- not have been made under the influence of other people
- be written down and be signed and witnessed if it relates to refusing lifesaving treatment.

What an advance decision cannot do

An advance decision cannot be used to:

- refuse treatment at a time when you still have capacity to give or refuse consent
- refuse basic care essential to keep you comfortable, such as [washing or bathing](#)
- refuse the offer of food or drink by mouth (but it can be used to refuse feeding by tube, for example)
- refuse the use of measures solely designed to maintain comfort – for example, painkillers (which relieve pain but do not treat the condition)
- demand specific treatment
- refuse treatment for a mental disorder in the event that you are detained under the [Mental Health Act 1983](#)
- ask for anything that is against the law, such as euthanasia or assisting you in taking your own life.

How to make an advance decision

The content of an advance decision can be as simple or as complex as you wish. It is up to you to decide how detailed you wish your decision to be. You can draft an advance decision yourself using your own words.

Unless it relates to life-sustaining treatment, an advance decision can be made verbally. There is no set format for making a verbal advance decision, as it would depend entirely on the circumstances, but there are a few things that you can do to ensure that it is still valid. Ideally, a verbal advance decision would still be recorded in your medical records by a medical professional as this can help avoid confusion later. The record should include:

- a clear note of the treatment(s) to be refused if you know that you will later lack capacity to make the decision yourself
- details about the witness to your decision
- whether the health professional heard your decision themselves.

However, it is advisable to make your advance decision in writing to ensure that the medical professionals are aware of your wishes and that they are understood correctly.

Talk to your GP

As an advance decision concerns healthcare, it is strongly recommended that you discuss it with your [GP](#) before drafting it. As well as providing information on how your illness is likely to affect you as it progresses, your GP can help you understand the advantages and disadvantages of choosing or refusing medical procedures in advance. They can advise on some of the problems that may arise from an unclear statement, and will also be able to confirm that you had sufficient mental capacity at the time that you drafted your advance decision.

Consider talking to a solicitor

You may also choose to talk to a solicitor. You do not need to consult a solicitor to draw up an advance decision, but if you are uncertain, a suitably qualified solicitor can help you to ensure that your views are clearly expressed. However, do be aware that a solicitor cannot necessarily advise you on how your illness will progress and the medical interventions that may be available.

Important information to include

If you choose to draft your own advance decision, this is the minimum information you must include:

- your full name
- your address
- your date of birth
- any distinguishing features (eg tattoos, birthmarks)
- the name, address and telephone number of your GP
- the date
- your signature
- the dated signature of at least one witness over the age of 18 – ideally not a partner, spouse, relative, anyone who stands to benefit under your will, or your attorney under a [Lasting Power of Attorney](#).
- the name, address and phone number of whoever you have nominated to be consulted about treatment decisions (eg your attorney under a [Lasting Power of Attorney](#) for health and welfare), if you have done so
- where relevant, the date that you reviewed – and, if necessary, revised – your advance decision, accompanied by your signature
- if the advance decision is applicable to life-sustaining treatment, a clear, specific written statement that the advance decision applies to the specific treatment even if life is at risk.

The following are not strictly required, but it is strongly recommended that you include them as well:

- There should be a statement to identify the circumstances under which the advance decision would come into effect. For example, it may specify that it would come into effect only in the case of terminal illness, and where you are unable to [make a decision for yourself](#).
- You should state any specific treatments that you wish to refuse, such as cardiopulmonary resuscitation (CPR) or artificial feeding and hydration. For more information on medical terms that you could include, and what they mean, you may wish to speak to your GP.
- It is advisable to include a statement in your advance decision to say that it was drawn up without influence or pressure from other people.

Make copies of your advance decision

As well as keeping a copy of the document for yourself, you should make several copies of your advance decision and give it to the following people:

- your GP, to keep with your medical records
- your hospital team, to place in your case notes
- a close relative or friend
- your attorney under a [Lasting Power of Attorney](#) for health and welfare.

Review your advance decision regularly

You are advised to review and, if you so wish, revise your advance decision or advance statement regularly. If you want to make changes, you can either start afresh and complete a new form or amend your existing document, making sure you sign and date it again to confirm the changes. Whether the original form is revised or a new form completed, you must ensure an independent witness also signs and dates the new version. Make sure you give copies of the revised version to all the holders of the original version.

Frequently asked questions

How long is my advance decision valid for, and do I have to renew it?

Your advance decision will be valid from the date you sign it. It is advisable to review and, if necessary, revise it to ensure that it continues to reflect your views. However, your advance decision will continue to be valid even if you don't review it. If you do revise your advance decision, remember to sign and date it with the current date and get it witnessed again. Make sure you know who has copies of your advance decision so that you can give them the revised version.

Do I have to give my advance decision form to my solicitor?

No. An advance decision is entirely separate from other legal documents such as your will. However, you may want your solicitor to hold it for safekeeping.

Does my GP have to sign the advance decision form?

No, this is not necessary, but it is useful. If you discuss your advance decision with your GP and ask them to sign it, they will understand your wishes better, and can also be called upon

if necessary to confirm that you had capacity at the time you made the decision. It is also important to make sure that a copy of your advance decision is placed with your medical records and to ensure that the relevant people know that it is there.

Can my family overturn an advance decision?

No. An advance decision is a statement of your wishes, and cannot be overturned by anyone, unless:

- you have signed a personal welfare [Lasting Power of Attorney](#) after the advance decision, and have given authority to the attorney to accept or refuse treatment to which the advance decision relates
- you decide for yourself not to follow the advance decision at a time when you have the required mental capacity
- you made your advance decision at a time when you did not have the required mental capacity
- you were unduly influenced by others to make the advance decision.

I have already written a living will. Is this still valid under the new act?

Living wills written before the [Mental Capacity Act 2005](#) came into force in 2007 may continue to be valid, provided they meet the new rules. If your living will includes a refusal of life-sustaining treatment, it needs to be in writing and to contain the important information described above.

We would recommend a Lasting Power of Attorney combined with if you wish an advance decision and or statement.

Further information

Difficult Conversations for Dementia

www.ncpc.org.uk/publications

Planning for your future care

www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare

Dementia UK

www.dementiauk.org

Dying Matters

www.dyingmatters.org

Alzheimer's Society

www.alzheimers.org.uk

FINANCE

The person you look after may be entitled to a range of benefits and there may also be some which may benefit a carer.

Please note these apply in the UK only.

The first place to look is the GOV UK website: www.gov.uk/browse/benefits as this information is kept up to date and you may be aware that there are some changes taking place with allowances etc. In order to ensure the accuracy of information.

Benefit enquiry line (they can talk you through the range of benefits available and tell you where and how to apply)

Freephone: 0800 882 200 Textphone: 0800 243 355 Monday to Friday, 8am to 6pm

The person you look after may be entitled to a range of benefits for things such as:

Disability living allowance: a tax free benefit paid at different rates depending on the disability - subject to assessment (This will change to a Personal Independence Payment - PIP for people aged 16 - 16 - beginning from April 2013).

Attendance allowance: for those aged 65 plus, to help support personal care needs

Pension Advice: Enquiries or to report a change in circumstances:

Telephone: 08456 060 265 Textphone: 0800 731 7339 Monday to Friday, 8am to 6pm

Pension credits: additional money to "top up" pensions to a minimum amount - the Pension Advice Line above can advise on this.

Income support: for those on low/no income

Council Tax support: A reduction in the council tax bill

Housing Benefit - help with paying rent

Winter Fuel Helpline: Telephone: 0845 915 1515 Textphone: 0845 601 5613

For those born before 5 July 1951

Disabled Facilities Grant - money to pay for adaptations to your home

NHS Benefit - free dental treatment and prescriptions: talk to the dentist, doctor and pharmacy about these entitlements.

The Blue Badge Scheme - to enable the holder to park in designated places allowing easier access to community services, shops etc. The Local Authority will administer this scheme locally. The GP will need to complete an assessment form to verify the need for a blue badge.

Initial Blue Badge Enquiry Support Service:

Telephone: 0844 463 0213 (England), 0844 463 0214 (Scotland), 0844 463 0215 (Wales)

Disabled Person's Bus Pass - subsidised or free travel. This is administered by local councils.

Disabled Person's Rail Card - gives a third off tickets: www.disabledpersons-railcard.co.uk/

Motability Scheme - cars, scooters or powered wheelchairs: www.motability.co.uk/

Direct Payments: Look at the page "Funding Care" for the detail.

Carer's Allowance

Telephone: 0845 608 4321 Textphone: 0845 604 5312

Monday to Thursday 8:30am to 5pm Friday 8:30am to 4:30pm

(there's also a useful fact sheet from Carers UK:

<http://www.carersuk.org/files/helpandadvice/71/factsheet-uk1025--carers-allowance.pdf>)

Just a thought:

By taking action on any one of these issues you can start saving yourself and your family and friends an awful lot of time, money and hassle.

We are always pleased to have a chat.

If you would like a free initial consultation then contact me Chris Berry at:

Address:

247 Church Street
Blackpool
FY1 3PE

Phone: 01253 620 022

Fax: 01253 297 117

Email: berrys.mail@btconnect.com

Website: <http://www.berrys-solicitors.co.uk>

Solicitor: Christopher Berry Principal

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