

 <p><b>St Helena Government</b></p>	<p><b>How to be a health and welfare donee</b></p>
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## 1. Getting started

This guide is for people who've been appointed donees under a Lasting Power of Attorney for health and welfare decisions or are considering taking on that role. It provides a summary of the information you will need as a prospective or actual donee. Please ensure that you seek legal advice as this guidance is not exhaustive as to the rights and responsibilities as a donee.

Being a donee under a Lasting Power of Attorney is an important responsibility. You need to understand fully what it involves before agreeing to accept the position – and you can refuse to do it if you feel uncomfortable about it.

Throughout the guide we use others' stories to show things that donees under a Lasting Power of Attorney consider when making decisions. These aren't final answers but may give your ideas about how to act.

An A-Z jargon buster at the end of this guide explains terms you might not understand.

### 1.1 What is a donee under a Lasting Power of Attorney?

In law, a donee is someone who's chosen to act on behalf of someone else.

When someone (called the 'donor') makes a lasting power of attorney (LPA), they pick people to make decisions for them in case they lose mental capacity. **Mental capacity means the ability to make your own decisions.**

The people chosen to help donors are donees. Donees don't need any special training but they do need to be trustworthy and reliable.

### 1.2 What is an LPA?

An LPA is a legal document that names the donee that is the person who'll make the decisions if the donor can't. You can make LPAs for health and welfare decisions, or financial decisions, or both.

This guide is for donees making health and welfare decisions for someone else.

### 1.3 Who can be a donee under a LPA?

Anyone aged over 21 who has mental capacity can be a health and welfare donee.

## **1.4 Should you be a donee?**

The person asking you to be his or her donee under the LPA believes you're the right person to make very important decisions for them about their health and care – sometimes including whether to consent to life-sustaining treatment.

If you haven't already accepted the role of donee, you need to think carefully about whether you're prepared to carry it out.

### **Things to think about**

- Would you have the time to help the donor, if ever they can't make decisions for themselves?
- Do you know the donor well enough to help him/her? If not, can you spend time now finding out what the donor likes / dislikes?
- Making decisions for someone without mental capacity can be stressful – could you cope with the demands of the role?
- Would you be confident making decisions in the best interests of the donor, even if other people wanted something else?
- If the donor is appointing other donees you'd have to work together. Would you find that easy or would there be conflict?

**The main rule for donees is that they must always make decisions in the donor's best interests – not their own or anybody else's.**

## **1.5 What sort of tasks will I do for the donor?**

Donors can leave specific instructions when they create an LPA but looking after someone's health and welfare often covers:

- where the donor lives and who they live with;
- the donor's day-to-day routine, including diet and dress;
- organising community care assessments and services for the donor;
- personal care of the donor, such as washing and dressing;
- arranging appointments for the donor with doctors, dentists and opticians;
- agreeing to or refusing health care for the donor.

A donee is not able to make a decision about accepting or rejecting treatment that could keep the donor alive ('life-sustaining treatment') unless the LPA expressly provides the donee with this decision making power.

## **1.6 When do I start acting as a donee?**

You can act under an LPA only if it's been registered with the Public Guardian (PG). If you're not sure if the LPA is registered, check with the donor or look at the LPA document. If it is registered, every page will have a mark saying 'Validated-PG'. If you are still not sure you can ask the PG.

If the LPA is registered, you begin acting for the donor when the donor has lost mental capacity in relation to the specific decision about their health and welfare that is to be made.

If you're unsure about the donor's mental capacity, you, the donor or someone else can arrange for an assessment by a GP or other medical professional.

## **1.7 Register now**

You should contact the SHG Safeguarding and Mental Health Teams for more information or the PG.

## **2. What does the PG do?**

The PG registers LPAs and investigates concerns about how donees are carrying out their role.

People who might raise concerns about the donor's physical or mental wellbeing include fellow donees, family members and others involved in the donor's care.

The PG has lots of information about being a donee but he cannot give legal advice – for that, you could speak to the Public Solicitor.

<b>Public</b>	<b>Guardian</b>
<b>the Castle – Jamestown</b>	

**+(290) 22470 ext 265**

[paul.mcginnety@sainthelena.gov.sh](mailto:paul.mcginnety@sainthelena.gov.sh)

## **3. What to do now as a donee**

### **3.1 Get to know the donor well**

If you don't know the donor already, find out about their likes and dislikes, values and views – either now or those they held in the past.

If the donor is still able to, discuss with them:

- where they want to live;
- if they follow any particular diet, such as vegetarian or vegan;
- their views on health care. If you are chosen in the LPA to make decisions about 'life-sustaining treatment', this should include what they would accept doctors doing to keep them alive;
- any political or moral outlook that shapes the decisions they make;
- what will happen if they cannot care for their pets;
- how they like to dress and wear their hair;
- their hobbies and tastes in music, TV, radio or books;
- if they prefer being indoors or outdoors;
- small things that cheer them up, such as a favourite film, a crossword, a glass of wine or a walk.

Write these things down or ask the donor to write down what is important to them.

If you do know the person who has made the LPA well, treat this as a chance to understand them even better.

The more you know about them, the better you will be able to make decisions if ever they cannot.

If they are no longer able to talk to you about their wishes and beliefs, then ask others who knew them well when you are making decisions.

## **Planning ahead**

Ask the donor if they have made care plans. These may include:

- a statement of wishes and preferences about their care and treatment (this might be written or told to people).

If the donor chose you in the LPA to decide about life-sustaining medical treatment and they lose capacity:

- you can talk to doctors as though you were the donor.

See if the LPA contains any instructions or preferences about how you should make decisions for the donor.

## **3.2 Get contact details and certified copies of the LPA**

### **Ask the donor:**

- for contact details of professionals such as their GP, dentist and optician; and
- where they keep the LPA document.

If the LPA is lost or destroyed, the PG can make copies.

If the donor has mental capacity, ask them to make official copies of their registered LPA document, known as 'certified' copies. You can use a certified copy in the same way as the original to prove you have permission to make decisions on the donor's behalf.

## **3.3 Start recording your decisions as a donee**

Once you start acting as a donee, you should keep a book where you record all the important decisions you make about the donor's health and welfare.

Significant decisions might include whether the donor should go into residential care, agreeing to medical treatment or making a change to the donor's diet for health reasons. You do not have to include small, everyday matters.

You could keep a written journal or create a file on your computer (saving a copy as a backup) recording the decisions you have made and when. You should include details of who you consulted about any decisions and any disputes about a decision.

## **4. Your role as a donee under a LPA**

### **4.1 What does mental capacity mean?**

As a donee, you will start making health and welfare decisions for the donor once they have lost mental capacity.

If someone does not have mental capacity, they lack the ability to make specific decisions – in this case, decisions about their own health and welfare – at the time they need to be made.

Someone may lack mental capacity because of a mind or brain problem such as:

- dementia;
- a serious brain injury;
- a severe mental illness.

The donor might be able to make some decisions, such as what they would like for dinner, but be unable to make more complex ones, such as whether to move into a care home.

Their mental capacity may come and go, so they may be able to make decisions at some times but not others.

### **Mental capacity: five principles**

The Mental Health and Mental Capacity Ordinance which governs how donees can act sets out five rules about people without mental capacity.

The principles affect you as a donee in these ways:

1. A donor must be assumed to be able to make a decision unless it is established that they cannot.
2. Before deciding that a donor does not have the capacity to make a decision, you should take all practical steps to help them make the decision.
3. If a donor makes an unwise or eccentric decision, this does not automatically mean that they lack capacity to make the decision. Many people with capacity make unwise decisions from time to time.
4. Any decision made on behalf of the donor when they lack mental capacity must be in their best interests.
5. When making a decision on behalf of a donor without capacity, you must consider whether the outcome can be achieved in a way that is less restrictive of the donor's rights and freedoms.

These rules should guide all your decision-making on behalf of the donor.

### **4.2 How can I tell when someone has mental capacity?**

The law says you need to reasonably believe that the donor lacks mental capacity in relation to the decision in question. Sometimes that just means considering the kinds of decisions they have made in the past and asking: Is it reasonable to think they probably still will – or will not – be able to make this decision today?

For example, if they have become confused in the past about decisions such as medical treatment or their living arrangements, it is reasonable to conclude they will still need help making such decisions – or be unable to make them.

But if they are usually able to decide about their diet, it would be unreasonable not to ask them to make such decisions.

If the donor's mental capacity changes you might need to check more often which decisions they can make. But if the donor's condition stays the same or is deteriorating, you might not need to check their capacity every day for decisions such as about what clothes to wear.

You can also ask yourself a series of questions to check the donor's mental capacity:

- do they have a general understanding of the decision that needs to be made?
- do they have a general understanding of the consequences of the decision?
- can they retain and weigh up this information to make a decision?

### **How to help the donor make decisions**

Sometimes you'll need to choose the right time and place to help the donor make decisions or you'll need to try different ways of communicating.

For example, the donor may be more responsive if you choose the right setting – they may be less confused in their home, rather than in an unfamiliar environment.

If the donor is usually livelier in the morning, that may be the best time to involve them in decision-making, rather than later in the day.

Sometimes the donor may just need more time for you to explain a decision.

Different ways of communicating might also help:

- try using pictures or sign language to explain a decision to the donor;
- perhaps the donor can point, squeeze your hand, blink or nod to show you what they want, even if they can't say anything.

Try to stay calm. It can sometimes take a while to make a decision, if someone is ill or unable to speak.

If you are still unsure whether the donor can understand and make decisions, you could ask their doctor to assess them. You could also ask friends, family and care staff who see a lot of the donor.

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### **4.3 Example: Telling when someone has mental capacity<sup>1</sup>**

When planning for her retirement, Joyce made a lasting power of attorney for health and welfare naming her son, Ralph, as her donee. She has now been diagnosed with dementia, and Ralph is worried that she's becoming confused about decisions.

Ralph starts by assuming that Joyce has mental capacity to manage her choices by herself. Then he considers each of Joyce's health and welfare decisions as she makes them, helping her if she needs it.

Ralph helps Joyce throughout a normal day and finds she can make decisions about what meals she'd like and what she wants to wear. But when Ralph asks her about visiting the doctor for an arthritis checkup, Joyce keeps forgetting when she will be available.

Ralph concludes that Joyce has mental capacity to deal with some everyday personal care matters but not other decisions involving timekeeping. He uses Joyce's LPA to arrange medical and dental treatments for her.

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#### **4.4 How do I make decisions in the donor's best interests?**

When you make decisions for the donor, the law says every decision must be in their best interests. You must not make a decision to suit yourself or other people – it has to be right for the donor.

Before making decisions for the donor:

- check the LPA for any instructions they have included – the law says you have to follow them;
- try to follow any preferences the donor has included in the LPA – you don't have to follow them but you should consider them when making decisions;
- consider the values and wishes of the donor – including any moral, political or religious views they have held;
- think about what the donor would have decided if they could;
- don't make assumptions based on the donor's age, gender, ethnic background, sexuality, behaviour or health – think about what they as an individual would want.

You should also ask whether the donor might regain mental capacity – for example, if their condition improves or they learn new skills. If so, can the decision wait until then?

#### **Asking other people**

The law says you must consult anyone the LPA says to consult about a particular decision or topic.

If you are making a decision about day-to-day matters such as leisure activities and diet, then care home staff may also be able to advise you.

If you are making a big decision, such as about medical treatment, then you will often need to consult a professional such as a doctor to show that you are acting in the donor's best interests.

#### **Best interests meetings**

If a decision is complicated or on a topic you do not know much about, you could consider calling a 'best interests meeting'.

As part of these meetings, a group of people involved in the care of the donor gather to share views on the best course of action. This process may help you to make a

decision in the donor's best interests. Professionals involved in the donor's treatment or care can arrange a best interests meeting.

Remember: keep a record of important decisions, who you consulted, any disputes and why the decision was in the donor's best interests.

#### **4.5 What can I not decide?**

You cannot:

- do anything that's not allowed by the LPA;
- make decisions about the donor's finances – unless the donor also named you as a donee in an LPA for financial decisions;
- agree to the donor getting married, divorced, dissolving their civil partnership or having sexual relations;
- make decisions that discriminate against the donor on the basis of their age, gender, sexuality or ethnic background;
- make decisions about treatment for a mental disorder if the donor has been sectioned.

#### **When someone else decides**

You don't decide everything for the donor – you can only make decisions in the areas the LPA says you can.

For decisions that don't fall to you, the decision-maker may consult you.

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#### **4.6 Example: Respecting a donor's beliefs and values**

Derek has been a strict vegetarian for most of his adult life. Some years ago, he appointed his daughter, Lucy, as his health and welfare donee.

With the onset of Alzheimer's disease, Derek is having trouble making many day-to-day decisions, including about his diet. However, Derek left instructions in his LPA that he should continue to eat only vegetarian food if he lost mental capacity.

He also said that whoever prepared the food shouldn't use utensils that have been used to make meals containing meat.

Lucy met with kitchen staff in Derek's care home to discuss how they can stick to Derek's food preferences. She also researched vegetarian meals on the internet and passed on suggestions to care home staff to keep Derek's diet varied and appetising.

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### **5. What should I do if... ? (Common health and welfare decisions)**



## **5.1 There's more than one donee**

The donor may have appointed two or more donees to make their health and welfare decisions.

When there is more than one donee, the donor can specify how they must make decisions:

- together (also called 'jointly'), which means all the donees have to agree on the decisions;
- separately or together (also called 'jointly and severally'), which means donees can make decisions on their own or with the other donees;
- together for some decisions and separately or together for other decisions, which means all donees must agree on decisions the donor specifies, but can make others on their own.

Joint donees have to agree on decisions but don't necessarily have to carry them out together. For example, as long as you have evidence of a joint agreement, only one donee might need to agree to a medical treatment.

If the donor does not specify how the donees shall make decisions, it is assumed that the donees must make them together ('jointly').

## **5.2 I need to decide where the donor lives**

You will often need to work with family and friends of the donor, as well as other care providers, to make decisions about the donor's living arrangements.

You should research accommodation that is right for the donor if they pay for their own care. If they do not pay for their own care, work closely with the Safeguarding Directorate to make sure their accommodation best suits their needs. If there is a problem, discuss it with social services and care staff.

You should not move the donor to a different place without consulting others such as family members, health professionals, care staff and social services.

If there is a disagreement, a best interests meeting may help resolve it. If you cannot arrange a meeting, you'll need to show you have formally consulted people involved in the donor's care.

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## **5.3 Example: Making decisions together**

Anna and Thomas are joint health and welfare donees for their brother, Nelson, who suffered severe brain damage after a car accident.

Thomas thinks Nelson's problems are demanding enough that he should move into residential care. But Anna points out that Nelson appears distressed when away from familiar surroundings for long. She suggests Nelson should move in with her or Thomas, if possible.

Anna and Thomas try to get Nelson's views but he seems to show little understanding of the decision that needs to be made. So they meet with the rest of the family to help decide where Nelson should live.

The donees listen to the family members before deciding it would be in Nelson's best interests to get used to living in residential care early on. They will decorate his room in the residential care accommodation with familiar items and visit him often, along with other members of the family.

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#### **5.4 I'm asked to consent to medical treatment for the donor**

Your decisions about the donor's medical treatment should always be guided by their best interests.

##### **You should:**

- sign 'consent to treatment' forms on behalf of the donor – taking into account their past wishes;
- share any instructions or preferences in the donor's LPA with care staff;
- follow the donor's wishes about medical treatment, even if you disagree with them.

##### **But you should not:**

- impose your own medical choices. Your decisions must be based on the donor's past preferences and best interests; treat the donor yourself or change prescribed medication or treatment without first consulting with health care staff.
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#### **5.5 Deciding about medical treatment**

James suffers from dementia and can no longer communicate well. He lives at home with his wife, Lena, who is his health and welfare donee under a LPA.

While on an outing with Lena, James cuts his leg and gets dirt in the wound. A doctor wants to give him a tetanus jab but James struggles and gets upset when the doctor tries to give him an injection.

The doctor discusses James' ability to make and understand decisions with Lena. Lena believes he doesn't understand the risk to his health, though she has tried to explain. James is unable to make the decision.

After speaking to the doctor, Lena decides it is in James' best interests to have the vaccination.

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#### **5.6 I need to make decisions about the donor's leisure and social activities**

Think about the donor's past preferences and how they respond now during leisure activities.

Arrange activities that the donor used to do, such as a trip into town or the country, an event such as Carnival or St Helena Day, etc. If possible, talk to the donor about leisure activities and outings they'd like.

Even if the donor does not show the same enthusiasm as they used to, you should not stop them from taking part in leisure or social activities they might enjoy.

Let residential care staff know if there are things the donor disliked doing. On the other hand, the donor might enjoy different things to what they liked when they had mental capacity as their preferences might have changed.

### **5.7 I want to claim expenses or be paid as a donee under a LPA**

If you wish to claim expenses or be paid as a donee you will require court approval. You will need to be able to explain to the court why the expenses have been or will be incurred or why you consider that payment is reasonable.

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### **5.10 I'm asked to make decisions about the donor's financial affairs**

As a health and welfare donee, you can only make decisions about the donor's finances if they have also appointed you as a property and financial affairs donee.

If the donor has appointed someone else as their property and financial affairs donee, it can be a good idea for them to consult you when they are making decisions that affect the donor's health and welfare. For example, they may be selling a house the donor used to live in but still sometimes visits.

### **5.11 I want to hand over my donee duties to someone else**

You cannot do this. You can seek expert advice about the donor's health and welfare but the law says you can't delegate your decision-making while you are still a donee. Ultimately, you have to make the decisions.

You can 'disclaim' your donee-ship if you no longer want to carry out the role. See 'When do I stop being a donee?' later in this guide.

### **5.12 There's a dispute about my role as a donee**

Sometimes disputes and disagreements occur over the decisions a donee is making for the donor.

Disputes can occur:

- between the donee(s) and donor;
- between donees themselves;
- with others who have an interest in the donor, such as family members.

## **Disputes with the donor**

If the donor disagrees with a decision you are making but you reasonably believe they lack capacity to make the decision, you can make it as long as:

- it is in the donor's best interests; and
- no instructions in the LPA prevent you from making the decision.

If you are uncertain about making a decision as a donee please contact the PG.

## **Disputes with others**

If donees acting jointly can't agree on a decision for the donor, please contact the PG for advice. The PG can also advise on resolving disputes between donees, friends and family members of the donor.

If you are challenging someone else's decision, you need evidence that the decision-maker isn't acting in the donor's best interests. You cannot simply disagree with the decision.

**You should keep a record of any disputes about your donee-ship and how they were resolved.**

## **6. Protecting the donor**

As well as offering donees advice and support, one of the roles of the PG is to protect people without mental capacity from abuse or exploitation.

Abuse is anything that goes against a person's human and civil rights. It can be deliberate or can happen because a donee doesn't know how to act correctly or lacks the right help and support.

Abuse by a health and welfare donee could include:

- violence, such as pushing or slapping the donor.
- threatening the donor.
- imposing your own beliefs on the donor.
- punishing the donor because they've been 'bad'.
- stopping the donor contacting other people.
- neglecting the donor, such as not providing medicine or food.
- involving the donor in sexual acts without their consent.

### **6.1 The Public Guardian's role**

The PG or his representative may arrange to meet you if he is investigating concerns about how you are acting as a donee.

The PG or his representative will usually meet you and the donor, or the donor alone, and discuss how you are managing your role. The PG will sometimes also contact others involved, such as family members or doctors.

The PG may seek legal advice from the Attorney General and where there are concerns that the donee is seriously failing to discharge their duties, the court may be asked to revoke (cancel) the LPA if the court decides that:

- somebody has pressured the donor into making an LPA.
  - the donee has done something the LPA doesn't allow them to do.
  - the donee isn't acting in the donor's best interests.
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## **6.2 Example: investigation by the PG**

Jack made an LPA appointing his son, Oliver, as his health and welfare donee.

When Jack lost capacity to make health and welfare decisions, Oliver registered the LPA and now makes many medical and care decisions for Jack.

However, other family members think Oliver might be abusing his position as a donee. They say he has prevented other family members he doesn't get on with from seeing Jack. Staff at the CCC where Jack lives also report that Oliver never takes Jack on outings, although Jack often seems happier when he has been on an excursion.

The family call the PG to discuss these concerns. The PG then goes to meet Jack and Oliver and assesses the facts of the case and starts an investigation.

As a result of that investigation, the Public Guardian will seek advice to decide whether the court should be involved. If the PG takes the case to court and the court thinks Oliver is abusing his position, then the court may cancel Jack's LPA.

## **7. When do I stop being a donee?**

You'll stop being a donee if:

- the donor dies (the LPA will automatically end);
- the donor revokes the LPA whilst he has mental capacity;
- you choose to stop being a donee; you are the donor's husband, wife or civil partner and get divorced or separated (unless the LPA says otherwise);
- you lose mental capacity and can't make decisions anymore;
- the court ends the LPA.

### **If the donor dies**

Send the following to the PG if the donor dies:

- a copy of the death certificate;
- the original LPA; and
- all certified copies of the LPA.

### **If you want to stop**

If you decide to give up the role of donee, you will need to contact the PG.

You should also tell any other donees named in the LPA.

If you are the only donee or have to make joint decisions with other donees and there are no replacements, the LPA usually ends if one of you stops.

If the LPA ends and the donor lacks capacity, someone will need to apply to the Supreme Court if they want to make decisions for the donor.

## **8. Glossary**

### **8.1 Abuse**

Abuse is a violation of an individual's human and civil rights by another person or people. Abuse may be a single act or repeated acts. Or it may be an act of neglect or a failure to act.

For a health and welfare donee-ship, abuse can include violence towards the donor, neglecting their care and stopping them from seeing people.

### **8.2 Donee**

Someone appointed under a lasting power of attorney (LPA) to make health and welfare or financial decisions for someone else (the 'donor').

### **8.3 Best interests**

Donees should always think about what action is in the donor's best interests when making a decision. You should also consider the donor's past and present wishes and think about consulting others.

### **8.4 Code of Practice**

A guide to the Mental Ordinance and Code of Practice (2016) that you can find on the SHG website.

### **8.5 Donor**

Someone who creates a lasting power of attorney allowing one or more persons ('donees') to make health and welfare or financial decisions for them once the donor no longer has mental capacity.

### **8.6 Lasting power of attorney (LPA)**

A legal instrument that allows one or more persons ('donees') to make financial or health and welfare decisions on behalf of someone else (the 'donor').

### **8.7 Least restrictive care**

If a person doesn't have mental capacity, decisions taken on their behalf must restrict their rights and freedoms as little as possible, while keeping them safe.

## **8.9 Mental capacity**

The ability to make a decision about a particular matter at the time the decision needs to be made.

## **8.10 The Mental Health and Mental Capacity Ordinance 2016**

The Ordinance is designed to protect people who can't make decisions for themselves. This could be due to a mental health condition, a severe learning disability, a brain injury or a stroke. The act allows adults to make as many decisions as they can for themselves and for a donee or others to make decisions on their behalf.