

Sharing the gift of life?

A guide to discussion and reflection on presumed consent and organ donation



Contents

1. Introduction
2. Arguments, concerns and issues to consider about presumed consent
3. Is there a distinctively Christian way of seeing the body – how might this relate to organ donation?
4. What ethical issues must be considered as the science of transplantation develops and laws change?
5. The rights and concerns of patients
6. Conclusions – Consent and Commitment

1. Introduction

1.1 The purpose of this discussion guide

Last year 1,160 lives were saved in the UK through the donation of organs such as hearts, lungs and livers. For the recipient, this donation can be life transforming, even life saving. Yet nearly 7,000 people are waiting for transplants, and three a day die without a transplant. The rules around 'consent' for organ donation are already changing in Wales and discussions about introducing similar changes in other parts of the United Kingdom have already started. This study guide has been created to help individuals and Churches reflect on some of the key issues around organ donation, including:

- why organ donation is an issue at the moment in the UK
- the attitude of churches to organ donation
- what consent is and why it matters
- our attitudes to the body, and why these are important to us
- medical and ethical issues of transplantation
- what it means to give and receive

Stories about organ donation frequently appear in the media. However they are often 'hard cases' or extreme situations. This guide offers a combination of real life stories, information, theological reflection and discussion questions to help all readers to engage with this debate.

Story

18 year old Aeron Griffiths had a seizure which left him brain dead. From a young age he had suffered from a brain condition which caused epilepsy and left him wheelchair bound. His condition meant that he had a mental age of 7.

Unlike a persistent vegetative state, 'brain death' means that the brain has suffered irreversible damage. Doctors will have explained that Aeron could not be brought back to conscious life, but that if allowed to die, his organs could be used for transplantation. They asked family for consent to do this, and they said yes.

His mother Mandy told newspapers how proud she was of her son in life and death. At least 2 people have been helped: a boy of 13 and a woman of 21, who received one of Aeron's kidneys and his liver. His mother did not meet the recipients, but said "As long as he had helped someone we did not need to know".

Aeron's whole family now carry organ donor cards and Mandy is all for the system of presumed consent that the Welsh Assembly has voted for, saying "it could save so many lives."¹

For Reflection

- 1) What are your first reactions to this story?
- 2) What do you already know about presumed consent and the proposed changes in Welsh law?

1.2 Background to the presumed consent legislation in Wales

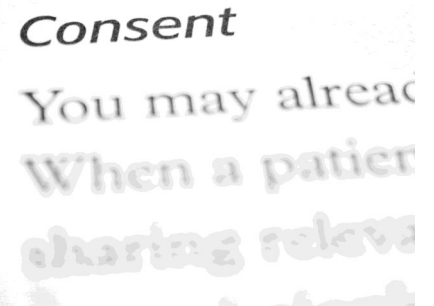
In July 2013 the Welsh Assembly voted in favour of 'presumed consent'¹ for organ transplantation. Under this legislation, unless people explicitly opt out, they are regarded as having given consent to their organs being available for transplantation. This is a change from an opt-in to an opt-out system of organ donation.

Northern Ireland is already holding a consultation on presumed consent, and it is possible that similar legislation will be debated in England and Scotland in the future.

Presumed consent raises many questions, both for Christians and for wider society. What do we understand by donating our organs or those of people we love? What is consent? Who owns your body? What is your body? When are you dead? Will presumed consent increase or decrease organs available for donation? Who has a greater moral say – the family of the organ donor or the person needing the organs?

It is important to remember that, under the current system, decisions about organ donation are often made by people who are overwhelmed by grief and urgent necessity. A death where it is possible to recover organs for transplantation is rare as well as unexpected. For individuals and families deciding whether or not to become donors, it may be valuable to consider and discuss these issues, whether or not the possibility of giving or receiving an organ ever arises. Ministers and others involved pastorally with patients and their families should also have the opportunity to reflect on organ donation and consent even if they have never (yet) been faced with this situation.

This resource has been prepared to help people to think through some of these questions before presumed consent comes into effect in Wales in 2015 or is discussed more widely through the rest of the UK. It can be used for personal reflection or to support a group discussion.



¹ The Welsh legislation uses the term 'deemed consent'. But the term 'presumed consent' is more commonly used in the wider debate, so it will be used in this document



Facts

- From 1 April 2012 to 31 March 2013, 1,160 lives were saved in the UK through a heart, lung, liver or combined heart/lungs, liver/kidney or liver/pancreas transplant and 3,052 patients' lives were dramatically improved by a kidney or pancreas transplant. 3,697 people had their sight restored through a cornea transplant.
- 1,000 people each year – that's almost three a day - will die waiting as there are not enough organs available.²

1.3 The history of organ donation and transplantation

Transplantation is the ability to remove whole organs, or tissue, from one living organism and put them into another. In addition to well known transplantation procedures like liver and heart transplants, organs such as the thymus, and tissues including skin, corneas, nerves can currently be transplanted.

The established practice of organ transplantation is little more than 50 years old.

- 1954: world's first kidney transplant
- 1963: world's first liver transplant
- 1967: world's first heart transplant
- 1970s: introduction of donor cards in the UK³

During this period, organ donation has been voluntary in the UK. But there is a quite a strong mismatch between people's stated attitudes to organ donation and current donor levels in the UK; when asked, 90% of people claimed they were in favour of donation, but only 31% of the population are on the donor register.

These figures suggest that people are largely in favour of organ donation in theory but this is not reflected in donation rates, with lives being lost as a result. Some argue that this is a strong reason for a move towards presumed consent. Others believe that while this would make some medical issues simpler, it would create other challenges.

For Reflection:

- 1) Have you or anyone you know given or received an organ? Do you feel able to share the story?
- 2) Have you registered as an organ donor? What was your reason for registering or not?

1.4 Churches' attitudes to organ donation

Christian Churches and other faith groups in the UK have traditionally seen the gift of organ donation very positively. Three important themes are:

The gift of life: medical science is able to use the organs or tissues of someone who is dead to save, potentially, several other lives. Donors can be living or have undergone brain death or cardiac death. The value of donation as a gift is particularly obvious in the case of live donors; to part with a kidney or other body tissues to save someone else's life or health is one of the most intimate and selfless gifts a person can give, giving, literally, a part of themselves.

Grace and meaning from tragedy: where an organ donor has suffered an accident, the gift of their organs may enable the gift of life in others and give a meaning to an otherwise tragic death. In some cases this may also be a strong comfort to the donor's family at a time of distress, as in the first story in this resource.

The value of voluntary donation: the Christian understanding of this gift traditionally involves the understanding that a gift can only be by consent, especially of something as fundamental as a part of oneself. The specialness of this gift is that it is a voluntary sacrifice.

1.5 Religion and Organ Donation



There are various factors that affect a person choosing to become an organ donor, or a family deciding whether to give consent to a transplant, including religion, culture and personal attitudes and feelings. These are often connected in quite complex ways.

Burial customs are one religious factor which may make families unwilling to agree to donation. In particular the need to bury the body by a certain time after death may make transplantation impossible. This has been a reason for some Orthodox Jews not to carry organ donor cards. However, in general Judaism approaches question of donation on a case by case basis and the National Health Service (NHS) guide, *Judaism and organ donation*, says “*in principle Judaism sanctions and encourages organ donation in order to save lives (pikuach nefesh). This principle can override the Jewish objections to any unnecessary interference with the body after death, and the requirement for immediate burial.*”⁴

There is a shortage of detailed research around the reasons that people refuse to allow organ donation. Anecdotal evidence suggests that transplant managers see religion as a key cause of families refusing permission for transplants, yet many denominations are extremely positive about organ donation. As the NHS leaflet on organ donation and religious perspectives says “*All of the UK’s major faiths including Buddhism, Christianity, Hinduism, Judaism, Islam and Sikhism support organ donation and transplantation. Many actively promote it.*”⁵ The NHS gives the following advice “*Anyone who has doubts as to whether their religion or faith allows them to donate is encouraged to seek advice from their local religious leader.*”⁶

It seems likely that a number of these concerns about organ donation are more a matter of personal belief than the official views of faith groups. A recent study⁷ shows the reasons that families gave in refusing consent for organ donation:

Did not want surgery to the body	24%
Patient had previously stated that they did not want to donate	21%
Patient had ‘been through enough’	21%
Family divided over decision	19%
Family unsure if patient would have wanted it	18%
Feared the body would be disfigured	15%

The study’s subtitle – ‘*it’s mostly a matter of respect*’ - implies the persistent feeling, of family members and others left behind, that the treatment of a dead person’s body still affects that person and not just the living.

Research suggests that people’s objections to organ donation cannot simply be described as religious. Another recent study found that the most common cause of refusal (44.4% of those consulted) was disbelief in the medical diagnosis of ‘brain-death’: that is, that doctors can prove by a brain scan that the potential donor is not just deeply unconscious, but could never return to conscious life. (The term brain-death is explained in greater detail below).

The survey continues:

Other causes were believing in a miracle (13.6%); fear about organ trade and unknown organ destination (9.9%); religious beliefs (8.6%); insecurity about the brain-death diagnosis (6.2%); unstable family mood (6.2%); unknown donor wishes about donation (4.9%); belief in body integrity after death (3.7%); and fear of objection by other family members (2.5%).⁸

It clear that it is the family's understanding of the donor's religion and their feelings about life and the body are key in any decision, and not just official religious views or rational, scientific conclusions.

1.6 The fleshandblood Campaign

fleshandblood is a campaign to encourage the church to see blood and organ donation as part of its giving. It aims to *"mobilise the church to increase the number of blood and organ donors in the UK, ...to recognise a need and respond with an act of generosity."*⁹ The Methodist Church, the United Reformed Church and the Baptist Union of Great Britain are associates of the campaign, as are the Church of England, Salvation Army, Church of Scotland, Church in Wales, The Evangelical Alliance, Hope, and the Seventh Day Adventist Church (supported by NHS Blood and Transplant).

The campaign points out that around 1,000 people die each year waiting for a transplant. (It also notes that 7,000 units of blood are needed every day to meet hospital demand with approximately 225,000 extra blood donors needed per year).

Other stories and study resources are available at the website fleshandblood.org

For Reflection:

- 1) Have you heard about **fleshandblood**? If so, have you got involved? If not, why not explore their resources at www.fleshandblood.org



2. Arguments, concerns and issues to consider about presumed consent

2.1 What is Presumed Consent?

'Presumed consent' is a system in which, after a person dies, their organs and tissues can be removed by doctors for transplantation, unless the person had explicitly 'opted out' by registering their objection. Welsh legislation coming into force in 2015 specifies that presumed consent only applies to those who have resided in Wales for 12 months and are over the age of 18. The term now used in Welsh law is 'deemed consent' which is equivalent to presumed consent.

Those in favour of presumed consent believe that it will save the lives of many who currently are dying unnecessarily, and dramatically improve the quality of life of those in need of transplants.

Others, however, believe that organ donation should only ever be voluntary, arguing that consent can only ever be voluntary and therefore "presumed consent" is a contradiction in terms. If conscious decision-making is removed from the donation of organs, there are fears that it may lead to a society in which people are increasingly seen as objects, whose organs can be, to use the pejorative term, 'harvested' at the will of the state or medical profession.

The issue for each system – voluntary donation or presumed consent - is that a person may not have registered their wishes before death.

- In a voluntary system, a person may have been willing to donate their organs, but if they failed to register the doctors have no power to act
- in a presumed consent system, even if a person did not wish their organs to be available for transplantation, their organs and tissues could be used by doctors unless they had opted out.

2.2 How did Churches respond to proposals for Presumed Consent in Wales?

Many of the Churches in Wales, as well as other faith groups, strongly opposed presumed consent although the Presbyterian Church of Wales and the Quakers took a more welcoming attitude to the legislation. The Churches that objected to the Act argued that organ donation is a gift of life and should be voluntary and include the family's involvement. They also suggested that presumed consent might not be the best way of increasing donation.

"...the most effective way to increase rates of both organ donation and family agreement to donation is to encourage people to sign the organ donation register, and to talk about the issue with relatives and those close to them."¹⁰

A joint statement made on 1 July 2013, signed by representatives of faith and medical groups including the Archbishop of Wales, The Wales Orthodox Mission, The Muslim Council of Wales, and South Wales Jewish Representative Council, said:

“When people have either opted out or opted in to organ donation, their wishes should always be respected. When however they have done neither, then the deceased family’s wishes should be sought and respected.”¹¹

The charity CARE conducted a ComRes poll which found that 94% of those polled said that families should have a right to object to donation if the wishes of the deceased were unknown. However, the implementation of the Welsh legislation appears to give a greater role to the family than some critics initially feared. The current guidance defines itself as a ‘soft opt-out system’ which it explains as follows:

Soft opt-out system	Family will always be involved and will be able to say if they know if their loved one did not want to be a donor. They will also be asked to confirm other details such as residency status and medical history.
Hard opt-out system	One where there is no family involvement. ¹²

The guidance also states that:

“In a deemed consent situation, family involvement is essential, to give a medical history, residency and possibly also a check on mental capacity. They must also be present to be allowed to provide information about whether the deceased objected to organ donation. If they know the deceased did not want to donate then donation will not go ahead.”¹³

This wording appears to be in between extreme 'hard' and 'soft' systems of consent. Donation will not proceed without discussion with the donor’s family, but it is not clear whether the family’s claim that they knew the donor’s wishes will be accepted without further proof.

Further information about the changes, including answers to frequently asked questions, can be found at the Organ Donation Wales website www.organdonationwales.org

For Reflection:

- 1) Do you think families should be involved in decisions about organ donation and transplantation? If so, what role should they have?
- 2) Should children be on the organ donor register? How would you discuss the issue with children?

2.3 Seeing presumed consent from different points of view

It is clear that people are likely to see organ donation and presumed consent from different points of view, depending whether they are patients awaiting a transplant (and their families), the families of potential donors, doctors or those who have a view based on ethical or religious principles. The perspective of those individuals who have been involved in organ donation in many different ways is particularly valuable. This is the story of Mary Jeremiah, a retired nurse practitioner, written in response to the legislation in Wales:

Story

Human Transplantation Bill - a personal response to the opt-out system

During the past forty years I have experienced different aspects of human organ donation and receiving, from both a professional and personal perspective.

In the 1970s in the early days of renal transplantation I was theatre sister in a renal theatre at a London hospital. I recall the excitement of the whole team as we transplanted the kidney of a deceased donor into a young man whose life had been blighted by renal failure. We had been privileged to play a part in offering this teenager a gift of life.

I felt moved by this experience and obtained my Organ Donor Card. It is significant that I did not carry a Donor Card previous to this, even though I had no objection. Talking about death and lack of education about donation have been shown to be barriers which result in no decision being taken to give consent to being a donor, even though one may have no objection. It is hoped that the new Bill will achieve the result of increasing the donation rate from those who had no objection.

My family had enormous gratitude for the donation of a heart lung transplant for my brother in law who lived in Australia. This allowed my sister and her husband to bring up their children into adulthood. The young donor died tragically in a water sports accident. This wonderful generous gift was possible because the boy and his family had talked about donation and made their views known to each other.

At the age of 35 my sister in law tragically died from a brain haemorrhage, leaving my brother with four young sons. At the hospital the doctor explained brain death to my brother, but he said that he could see that life had gone. My brother and his wife knew about organ and tissue donation and had talked about it with the family and he gave consent straight away. Grateful families have since written to him and I know this has given us all a satisfaction that the opportunity was taken. Fifteen years later, my brother says it was the right thing to do and would feel bad now if he had not given consent. The boys say that they are proud that they have done this to help several people.

Our first child was born with Cystic Fibrosis, a life-shortening inherited condition affecting over 10,000 people in the UK. It leads to respiratory failure and at present the average life expectancy is 31 years. The Cystic Fibrosis Trust supports any move that means more people with Cystic Fibrosis will have a chance of receiving a successful transplant. The Better Life Appeal charity supports the Cystic Fibrosis Centre for Wales. They are currently seeking funding for portable ventilators which can be used to help youngsters breathe long term whilst waiting for a lung transplant. There are families breaking their hearts watching their child suffer, hoping for a donation. Our son was not offered a donation of the gift of life and he died at the age of 29.

When tragedy or disaster visit your house you often look at life in a different way. It's difficult to imagine the horror of needing a transplant or finding yourself in the position of you or a family member being a donor. It has been shown that talking about this between family members and making your views known results in an increase in donation. As a health professional I have been in the nightmare situation where a young boy died following being hit by a car. In retrospect, if the mother had previous knowledge of donation, consent may have been more likely. Similarly, a young motorcyclist's death did not result in donation.

Countries that operate an opt out system exhibit 18% higher donation rates on average compared with opt-in countries. However, it must be stressed that health professionals approach every case in an individual caring way and this will continue with implementation of the new bill in 2015.

Mary Jeremiah, May 2014

For Reflection:

- 1) What are your reactions to Mary Jeremiah's story?
- 2) Do you think the debate about presumed consent might change if more people had personal involvement with organ donation?

2.4 The importance of ensuring fairness and respect in the treatment of organ donors, recipients and families

In cases where the donor is not considered capable of giving consent, such as the story of Aeron Griffiths above, the power to give consent has traditionally resided with the family. The NHS provides a leaflet to inform people with learning disabilities about organ donation¹⁴. Clearly, this is an attempt to create awareness and assent among those who may be disadvantaged by the need to understand the issues. Yet there are serious potential justice issues – does presumed consent mean that some people who are mentally incapable of ever giving consent can be treated as legitimate donors?

In a system of presumed consent, there may be difficulties if the family objects to transplantation. This may not just have a devastating effect on families, but may even be counterproductive to the aim of increasing donation. For example, in February 2007 in Singapore, the corneas and kidneys of Sim Tee Hua were transplanted. Singapore already has a system of presumed consent, but in this case the family was strongly against the transplantation. The case received a lot of publicity and led to many Singaporeans opting out of organ donation in protest¹⁵.

On the other hand, under present rules, even if the potential donor has said that were willing to donate their organs, unless they have registered, their family has the final say. The campaign to publicise the new legislation in Wales¹⁶ may result in a greater number of people's decision about whether to donate their organs being known and respected, whether they decide to opt out or stay as potential donors.



For Reflection:

- 1) The deceased donor may have been pro or anti donation or not have thought about it. What difference, if any, does this make to whether the feelings and rights of the family should be respected in a system of presumed consent?
- 2) What say do you think that the family should have in whether a deceased relative's organs/tissues can be used for transplantation? Would it make a difference if there were reasons to think the family might have different religious or ethical views to the deceased, or didn't fully understand the deceased's views?

2.5 To whom does your body belong?

Story

A 41 year old mother was denied a kidney transplant from her dying daughter. Her 21 year old daughter wished to give her mother a kidney but died before she could become a living donor. Her mother subsequently died, but before she died she said "I am not finding comfort at the moment in the fact that she helped three people. She would have been so upset that she was able to help other people and not her own mum. Everyone has gone mad and everyone is disgusted. The thing that hurts the most is how Laura would feel. She would be devastated that she was not able to help me."¹⁷

Most of us have probably never considered the question 'who owns my body?' It sounds strange because we do not think of the body as something that can be owned. Yet as presumed consent or related legislation spreads, we may increasingly have to think of bodies and organs in terms of who has rights or claims to them, or parts of them.

Traditionally the choice of **what** to do with the body was prompt cremation or burial, unless the circumstances of death required a postmortem. Condemned criminals' bodies were sometimes used for medical research, due to the feeling that they had forfeited their normal rights through their crime and could pay their debt to society back by aiding medical research. But progress in organ transplantation means that increasingly, we need to think about our attitudes to the human body.

It is a well-established principle of law that there can be no 'ownership' of a dead body. However certain people have the right to possess the body, for example if they have a duty to bury it. But this legal definition may not reflect what people *feel* should happen after their death or the death of a loved one, and that next of kin should be able to make decisions as they have a claim to the body.

Yet thinking of rights in terms of ownership can incline us to an individualistic or competitive view of the treatment of bodies, even a dehumanizing one which sees people as property. Sometimes the sense of a tension between an individual's rights and that of others, eg doctors or the state, emerges in the fear that presumed consent legislation may be the 'thin end of the wedge' to a society in which we no longer 'own' our bodies. If a deceased person was an organ donor, would it mean their body was now the property of the NHS?

The feeling that each person should have the main say in what is done with their body as with their other possessions after their death is reflected in our word 'Will' for a legacy: that a person's wishes survive their physical death and that their body or corpse is in some way a possession of theirs to be disposed of according to their will. If they do not make a will, responsibility will generally pass to the next of kin.

But this view and the language of 'ownership' may be criticized as being too individualistic. Each one of us belongs to wider society in various ways; through networks of connection including family, ethnicity, nationality and shared belief. These networks are the context for sharing and ties of love, obligation and trust. Blood donation is already an accepted part of society in the UK and as the debate around presumed consent goes forward, we are challenged to consider our wider ties of belonging and what they mean for rights and claims concerning bodies, and also to think more deeply on how our views about the living body relate to those about the dead body.

For Reflection:

- 1)) Does your body belong to you alone, to another (eg family, God or the state), or is 'belonging' more complex than that? Who has a right to determine its treatment after you die? How does this relate to the story above of the mother denied her daughter's kidney?
- 2) How do you think this might apply to products of your body like blood, or genetic material which may be used when you are still alive and also after death? Do you think organ donation should be seen differently from blood donation and if so, why?

2.6 The role of authorities in decisions about organ donation

Our experience of death, illness and bereavement often involves engaging with authorities – doctors, the state, and religious leaders (for those of faith). Traditionally in the UK the family, specifically the next of kin, took responsibility for the deceased's body, unless the person was a registered donor. When the next of kin are approached about the possibility of organs being transplanted from a dead or brain dead person, they are required to make a very hard decision. For a family dealing with grief and painful decisions, the feeling of being caught in a bureaucracy may add to the stress.

Having discussed transplantation informally at a previous time may not be enough to help. The next of kin may have different, or differently interpreted, religious convictions about transplantation, or they may simply be unable to conceive of allowing transplantation due to grief.

For Reflection:

- 1) Most of the debate around organ donation has been between those with professional authority, such as doctors, the state and Churches. Do you think any other voices are missing from the debate and if so, whose? What might they say?

3. Is there a distinctively Christian way of seeing the body – how might this relate to organ donation?

3.1 Christian and traditional views of the body

People have deep feelings and beliefs about bodies. These are central to various religions, but also underlie the attitudes of many people irrespective of any religious beliefs. There are three common views of the body that surface when people think about their feelings about bodies and transplantation, which can be called the 'magical', 'mechanical' and 'Incarnational' views.

3.2 The magical view: are people identical with their blood, tissues or organs?

Story

Charla had worked on transplant cases at Tampa General, where her 31-year-old daughter, Liane Adgate, was now on life support. She knew how many people were waiting for organs, hoping to get a second chance. She said she wanted to meet the recipients. Maybe, in them, she would still see Liane. One day she hoped to press her hand against a stranger's shirt and feel her daughter's heart still beating.¹⁸

It is part of human nature to see people as very closely identified with their bodies – not just the outer appearance but all the parts of which they are made. Numerous cultures throughout human history, particularly in earlier times, have had the belief that a person's essence literally resides in their head, heart or other organs. Historically, this has led to practices that may seem inexplicable to modern people like eating parts of animals to ingest their strength, their 'spirit', or even to human sacrifice. A number of these practices are still followed in some countries and communities.

Modern science has generally seen this view of the world as superstitious and many theologies within and outside Christianity would see this as religiously misguided. It could be called a fetishistic or 'magical' view, seeing bodies as full of mysterious power and life which contains a person's being, particularly the blood and the organs.

Even if, rationally, few people in our society would claim that bodies or body parts can contain the essence of a human being, we sometimes feel or act *as if* we did believe it. There seems to be a persistent feeling that there something of a person dwells in their brain, heart or blood. Many of us have heard stories of recipients of blood or organs feeling that a foreign personality has entered their body. Whether these are scientifically credible or not, they show people's deeply instinctive response to the idea of 'other bodies' entering them.

If a person were identical with their body, there would be serious issues about organ donation. This would mean allowing a part of oneself to be lodged inside someone else, and if God created us entire, some might feel donation to be against God's will, because if our essence were bound up with our body, blood and tissues, it might not be ours to give. Belief in the sacredness of blood is associated with kosher and halal food regulations and plays a role in the Jehovah's Witnesses' views, which is why they only allow transplants if the blood is drained from the organ.

This view of bodies is often close to the surface when people say it would be disrespectful to the deceased to mutilate the body, or that it might prevent them from living in the afterlife, or that it is 'all that is left' of them. Yet it also can provide solace to those like Charla in the story above, who believe a loved one 'lives on' in their organs.

For Reflection:

- 1) Do you think people's essence is contained in their organs or blood? How does this relate to your religious or scientific views?
- 2) Would this make this uneasy about giving or receiving an organ? Or would it bring comfort as in the story of Charla?

3.3 The mechanical view: Is the body nothing but a machine? And if so, what really is a person?

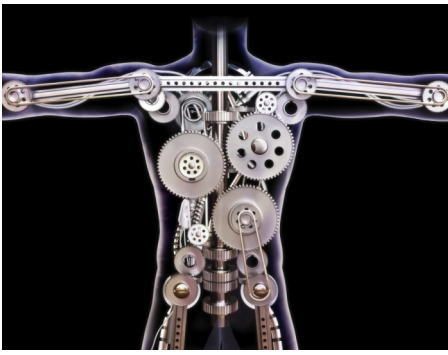
Story

Aubrey de Grey is a geneticist who believes that the human life span may be extended to 1,000. He said "Ageing is a physical phenomenon happening to our bodies, so at some point in the future, as medicine becomes more and more powerful, we will inevitably be able to address ageing just as effectively as we address many diseases today".

"There is no difference between saving lives and extending lives, because in both cases we are giving people the chance of more life... To say that we shouldn't cure ageing is ageism, saying that old people are unworthy of medical care."

"... some people are worried that it would mean playing God and going against nature. But it's unnatural for us to accept the world as we find it. Ever since we invented fire and the wheel, we've been demonstrating both our ability and our inherent desire to fix things that we don't like about ourselves and our environment. We would be going against that most fundamental aspect of what it is to be human if we decided that something so horrible as everyone getting frail and decrepit and dependent was something we should live with forever."

"If changing our world is playing God, it is just one more way in which God made us in His image."¹⁹



Science, religion and philosophy have developed numerous theories and technical terms to describe the different aspects we can identify in human beings. As well as the body, this would include our thoughts, wishes, instincts and emotions. For psychologists it might include a subconscious while some religions (but not all) would speak of a soul or spirit. Different theologies or philosophies may point to a tension between the 'mind' and the 'body', where the mind is identified with our rational side and the 'body' with our desires and sensual nature.

Whether or not we believe in a separate mind or soul, it is usual in modern Western society for people to identify more with their feelings, memories and other aspects of their personality than with their bodily appearance. As you get older and donate or receive an organ, you are still 'you'. There is no one English word that captures this you which relates to the body but is not limited by it. The closest is perhaps 'person' so that term will be used here.

Some people do not identify their personhood with their body, such as people who feel they have been born into the 'wrong' body. Others feel they are more than a body. For them it can become quite complicated to decide how they relate to the human body. Some believe that humans have, or are, a 'soul' or 'spirit' which outlives the body in an 'afterlife'. This has sometimes led to religions and philosophies which think that the body is not really part of the person or that these two parts of us are at war. That in turn has often led to the view that the body must be controlled or, if necessary, punished.

Ironically, the idea that matter is different from the human person, and that the body is essentially mechanical has been promoted by two kinds of people who on the surface seem very different:

- some scientific materialists and atheists, who think we are just bodies and our 'mind' is simply a product of the brain
- extreme 'spiritualists' or dualists who believe in a spirit or mind which inhabits the body much like a 'ghost in a machine'

On this view, there is arguably no real problem with transplantation, as the body is a kind of robot. Human persons 'possess' bodies which are basically machines which may need replacement parts, much as a car may need new tyres or a new engine. Since the 17th century much of our Western science and medicine been based on similar views.

Medicine has made remarkable progress through treating the human body scientifically in the same way as the rest of the natural world. This has enabled the breakthroughs that enable organ transplantation and some scientists, like Dr De Vere quoted above, have an optimistic view of science as fixing what is wrong with nature and enabling humans to live in good health to ages that would have seemed incredible for most of human history.

It is interesting that, as a scientist, Dr De Vere addresses the concerns about 'playing God'. Many people, even those who would not identify themselves as particularly 'religious', have reservations about 'tampering' with nature, as if on some level, they fear that a technological approach to the body would dehumanize them. Yet our lives have already been vastly changed by modern scientific medicine, and doctors can point to advances in the length and quality of our lives that the scientific approach has brought.

At first glance, reflecting on the relationship between the body and the mind may seem to be a purely theoretical issue, of interest only to theologians or academic philosophers. In actual fact it plays a powerful role in ethical decisions we make as individuals and societies, for example:

- if nature is just a machine, then humans have no moral duties to other species or the environment, unless it impacts on them. Some even think animals have no true consciousness, so that humans are free to treat them however they wish including performing vivisection.
- If people are machines who are mere assemblages of parts and medicine is essentially a technology, this raises questions about the relationship between those who control this technology, and society. This underlines the common, if emotive, language around people being 'harvested' for body parts.

Green and feminist ecologies have been very critical of the harmful effects of this 'dualistic' thinking on society and the world, particularly on those oppressed by technology and power. Yet it remains deeply embedded in our culture; our human sense that we are more than a body, yet not separate from it and the power of Western science to understand and shape our material world remain challenges that we must meet, and the likelihood of increased organ donation in the future makes this all the more important.

For Reflection:

- 1) Do you think that human bodies are machines with replaceable parts? What are the advantages or dangers of this way of seeing persons?
- 2) Do you think of yourself as a mind, soul or spirit inside a body? Does this influence the way you think about organ donation and consent?

3.4 The incarnational view: the breath of God

Story

Angela Griggs's story is told on the **fleshandblood** website. She is a mother of two girls, and a lecturer/practitioner ENT nurse who required blood after a difficult labour. In her words:

"I've been putting blood up for patients for over 16 years in my job and I knew a lot about having a blood transfusion and the checks involved but when you have blood yourself you finally realise the impact it has on the patient.

Now I'm much better at looking after my patients. If they need blood it's actually a lot easier to explain to somebody when you've had a blood transfusion yourself and can say 'I've done this.'"²⁰

Another approach to looking at organ donation might be to begin from a theology of life as a gift connected with a particular interpretation of the Biblical language around 'the breath of life'. In Genesis we are told that "God created humankind in his image..." and that the breath of God, breathed into the nostrils, created a living being. This story might help us to see our bodies as coming from God, but our life is not 'locked up' in our bodies as some kind of personal possession. The image of God's gift of the 'breath of life' strongly suggests that, like the air, life is something which passes in and out of us, a shared atmosphere in which we live.

Theologically, it may even be that one reason we struggle to understand the relationship between persons and bodies is that the integrity of creation itself, including the right relationship between humanity and the rest of nature, was marred by the biblical 'Fall'. For Christians, Christ's incarnation is the central act in God's work of reconciliation and redemption – of humans with God, with each other and with Creation. So, what light might the incarnation shed on a theological understanding of organ donation?

We can reflect that the incarnation and God's work in making us one body in the unity of the Holy Spirit has deep social consequences. It implies that persons and their bodies are part of the bigger body of a community or society. Christian theology affirms the role of the Holy Spirit in binding together the life of believers as part of the mystical - and risen - body of Christ. The issue of blood and organ donation challenges us to reflect on what it is to be part of this Christ's body, physically and spiritually.

The incarnational principle of Christianity may not only be good theology, but good medical ethics supporting a view of life, and the organic tissues in which it lives, as something that can be shared and through which healing and reconciliation may occur. Just as incarnation spirituality sees bodies as created by and potentially pervaded with Spirit and God's grace, perhaps it can help us think about organs, tissue and blood in a new way; neither as 'dead stuff' nor as personal possessions, but as an endowment shared between us, like air.

There are also deep environmental implications to this. An ecological or green theology sees stewardship as part of our interconnectedness with God's creation, and the life within us and linking us together as pervaded by the Holy Spirit. Yet if we feel that nature is completely dead and mechanical and has nothing to do with the Holy Spirit or the human spirit, we will be more likely to treat the planet abusively.

For Reflection:

1) *"Do you not know that you are God's temple and that God's Spirit dwells in you?" 1 Corinthians 3:16*

The 'you' referred to in the above verse from 1 Corinthians is plural: the Corinthians were being told that God's Spirit dwelt in the company of believers and not just in the individual. How do you respond to the view of life as a God-given, common gift, and to incarnation spirituality as having implications for what it means to be the 'body of Christ'?

2) How does the Bible help you to reflect on transplantation, organ donation and consent? Are there particular passages or stories which are helpful for you? How does your understanding of message of God through the Bible interplay with other perspectives you might have (eg reason, experience, science or emotion)?

3) Is your view of the body, the mind and life similar to any of the three views described above, or do you have a different view? If so, what is it?

4. What ethical issues must be considered as the science of transplantation develops and laws change?

4.1 Fears and controversies about the diagnosis of death

Story

After a car crash, 19 year old Carina Melchior had had life support withdrawn on the advice of medics and was being prepared for organ donation. She regained consciousness just before the procedure began. The website www.medicaldaily.com reported as follows:

"... to the astonishment of the staff at the Aarhus University Hospital, in Denmark, Carina suddenly opened her eyes and started moving her legs.

"However, her family is now suing the hospital for damages, claiming that doctors took her off life support too soon because they were desperate to harvest her body parts.

"Those bandits in white coats gave up too quickly because they wanted an organ donor," Carina's father Kim told the Danish newspaper Ekstra Bladet."²¹

Stories about people coming back to life after a diagnosis of brain death may often be urban myths, but they are likely to feed a fear of organ donation for some people. The story of Carina Melchior received considerable online coverage in October 2012, especially on websites which represent skeptical views about, or are opposed to, donation. The Daily Mail also reported on this story²². It is notable that press coverage included the quotation from Carina Melchior's father describing the doctors concerned as 'bandits', against the background of legal proceedings.

Questions about organ donation frequently happen against a backdrop of tragedy and grief, and it is hard to imagine the feelings of Carina Melchior's family following her sudden awakening. Yet a contrary voice might suggest that the fear and exposure such cases generate is out of proportion to their extreme rarity, whereas many other medical mistakes or accidents are not covered so emotively.

Despite the fact that the use of electrical scans to establish brain death is widely accepted and current criteria for the 'brain death' diagnosis are extremely stringent, the issue clearly remains one which is frightening to people. The 'extreme cases' which are reported in the media feed a fear that a diagnosis of death may be wrong and even fuelled by a desire for organs. This is a fear that needs to be heard even if it is wildly exaggerated. It challenges ongoing medical research and assurance that the system is working well and inspires trust. And it challenges us all to reflect on how we respond to stories that we hear in the media and elsewhere.

For Reflection:

1) Have you encountered stories like these? How did you respond? Do they change the way you view organ donation and transplantation? And do they affect your views about presumed consent?

4.2 The challenge of data management at a time of change in the NHS

The NHS is currently going through a period of major reorganisation. In a context of potentially increased privatisation, who owns sensitive data around presumed consent and how can data ethics be maintained during a period of continual change? Assurance around the donor register is also important; the Welsh legislation specifies that presumed consent only applies to those who have resided in Wales for 12 months and are over the age of 18. Yet for someone who has recently died, every minute makes a difference to the viability of organ transplant. Will it be possible to establish the residency of someone killed in an accident in time?

4.3 Medical and scientific ethics, and the right to decide on the use of bodies and organs

As science advances, it has the potential to lead to new possibilities and obligations around organ donation. If the medical breakthroughs that allow a person to live an extra 50 years with a donated kidney were paid for by the NHS, should bodies should be seen as state-owned or communal? At the moment, many concerns about organ donation and consent are theoretical, but typical questions asked include:

- If a private company patents a genetic technology, could they own rights to the bodies of those helped?
- Does a donor of blood, organs or tissues have any rights to say how their donation is used in the future, or is this decision entirely in the hands of doctors?
- On the other hand, if bodies are communal, then just as we are part of society and the entire human species, should it not be valid for an organ that grew in one person can be transplanted to another?

For Reflection:

- 1) What ethical issues concern you most about scientific developments?
- 2) What would help to minimize your concerns and the risks to ethical behaviours and practices?



5. The rights and concerns of patients

Story

The Revd Michael Corney is a Methodist minister in Norwich and the recipient of a liver transplant. Following his transplant, he wrote the following prayer:

Transplanting God,
You suddenly shine a light in the darkened rooms of long illnesses and struggles.
You bring hope to birth in deepening weakness for those who desperately wait and pray.
You inspire donor families to offer new life from the deep pain of their grief and loss.
You empower and inspire clinicians and surgeons to make transplants possible.
You embrace those receiving transplants through the love of families and friends.
When life seems to be running out, you sometimes have other ideas.
For into darkened rooms the sunshine somehow finds a window.
Transplanting God, we celebrate your sign of hope in those who have had transplants
and in so many others who still wait. Amen.²³

***You received without payment;
give without payment”
Matthew 10:8 (NRSV)***

In any conversation about organ donation and presumed consent, the views of those who are seriously ill and awaiting transplants must be considered. Under the current system patients on waiting lists must live with the knowledge that they may be denied the possibility of a life saving transplant which could be available to them through the change to an opt-out system.

The issue of the rights and needs of those waiting for transplants is complex and goes beyond debate about presumed consent. For example, people of different ethnic backgrounds have varying needs for transplants. According to research published in the British Medical Journal, members of ethnic minorities have a disproportionate need for transplants but are less represented on the organ donor register than other members of society. This research also noted that minority ethnic people cite ‘many concerns’ about organ donation relating to distrust, or religious or sociocultural issues²⁴.

A system of presumed consent would not necessarily meet these concerns on its own, particularly those of members of ethnic minorities, but it could have the significant social benefit of giving assurance to those waiting for transplants that their needs will be met.



For Reflection:

- 1) What do you think the rights of a would-be transplant recipient are? How should these rights affect our view of systems of presumed consent?
- 2) How do you think you would feel if you or your family were in this situation?

6. Conclusions – Consent and Commitment

So what should Christians and churches be doing in the debate over organ donation and presumed consent? Many ministers, chaplains and others offer much needed pastoral support to those who are giving or receiving organs and to their families. Churches still play an important role in providing a way for people to mark the rite of passage of death. For Christians, the liturgy of the funeral service affirms God's eternal love and gift to us all. The process leading to presumed consent legislation in Wales showed that many churches and Christians, though not all, are deeply committed to voluntary organ donation and would oppose changes that presume a person's consent to organ donation rather than seeing it as a considered gift. How therefore can we bring our perspectives, understanding and experiences to the debate around presumed consent?

Three principles are suggested:

1. Organ donation is a good thing.

Churches have a developed theological, political and practical understanding of the value of organ and tissue donation. If existing levels of voluntary donation are insufficient to meet the need for transplants, are we being called to lead by example and to raise the issue of donation in society? The **fleshandblood** campaign is a response to this situation and it is hoped that Christians will continue to engage with it

2. Yet *presumed consent* remains an uneasy principle.

The advantages of an opt-out system of organ donation are very clear; many lives could potentially be saved. Yet the importance of consent cannot be ignored. Consent is a vital concept legally and, more importantly, morally. Such consent should be sought actively, and before a time of crisis. Giving a gift of life, as a voluntary offering of something as intimate as part of one's own body, should truly be a gift which is offered freely.

As new legislation is tabled and introduced across the United Kingdom, whether for presumed consent or another, softer, version of an opt-out system, Churches should publicise these changes widely and encourage discussion. Christians should continue to be encouraged to become voluntary organ donors.

3. Churches have a role that is both pastoral and public.

Individuals, ordained or lay, offer pastoral support in situations of donation, whether it is the wordless presence of a chaplain or the minister's preparations for the funeral. Our churches provide somewhere where people can grieve and be together as part of a worshipping community. These are clearly crucial roles, that our people and churches should be resourced and supported to do. But the pastoral care begins before the point of crisis. Do we give people the opportunity to think through organ donation and their feelings about it in advance? Do we help people to explore the ethical and theological issues?

Death is a time when families come into contact with 'the authorities' – medical, legal, state, even those in 'religious authority'. The ability to trust

these authorities to be working 'on your side' humanizes the appalling experience of grief. Do Churches also have a role to speak out for systems which are transparent and build public trust? Do Christians have a responsibility to engage with medical ethics and scientific developments?

The third suggested principle is that our response as Church is one which should be both pastoral to those who are in need and have a public dimension which envisions a society where the potential of the wonder of organ donation can be fulfilled.

Final Reflection:

- 1) Do you agree with these three principles? Do you think there are different principles that the Church should adopt?
- 2) Having read this document, do you think Churches should lead by example and promote discussion of organ transplantation and voluntary donation? If so, how?
- 3) What do you want to know more about or explore further?

Endnotes

1. Reported on 11 August 2013 at www.walesonline.co.uk/news/health/why-believe-presumed-consent-could-5694071
2. <http://www.organdonation.nhs.uk/statistics/>
3. <http://www.nhs.uk/Tools/Documents/transplant.htm>
4. http://www.organdonation.nhs.uk/newsroom/fact_sheets/religious_leaflets/judaism_and_organ_donation/judaism_and_organ_donation.pdf
5. http://www.organdonation.nhs.uk/newsroom/fact_sheets/religious_perspectives.asp; NB - “Against broad religious acceptance of organ donation to aid the sick stand three major exceptions: Jehovah’s Witnesses, Christian Scientists, and the Shinto faith” – see <http://www.beliefnet.com/Faiths/2001/05/Organ-Donation-Where-Your-Religion-Stands.aspx?p=2>
6. http://www.organdonation.nhs.uk/newsroom/fact_sheets/organ_donation_registry_fact_sheet_3_21337.pdf
7. http://www.academia.edu/817382/Relatives_refusal_in_organ_donation_its_mostly_a_matter_of_respect
8. <http://www.ncbi.nlm.nih.gov/pubmed/21440717> see also http://www.organdonation.nhs.uk/statistics/presentations/pdfs/poster_apr-sep03.pdf
9. <http://fleshandblood.org/>
10. <http://www.senedd.assemblywales.org/documents/s14686/7%20February%202013.html?CT=2>
11. <http://www.churchinwales.org.uk/news/2013/07/5648/>
12. <http://organdonationwales.org/FAQs/Organ-donation-from-december-2015/?skip=1&lang=en>
13. <http://organdonationwales.org/FAQs/Organ-donation-from-december-2015/?lang=en>
14. https://www.organdonation.nhs.uk/newsroom/fact_sheets/language_leaflets/organ_donation_ld.pdf
15. <http://www.bmj.com/content/345/bmj.e5275?tab=responses> see also: http://www.academia.edu/2203112/Respecting_the_family_is_key_in_any_viable_organ_procurement_policy
16. <http://organdonationwales.org/splash?orig=/>
17. <http://www.dailymail.co.uk/news/article-1208480/Mother-dies-doctors-refuse-save-life-transplant-using-daughters-kidneys.html>
18. <http://www.tampabay.com/features/humaninterest/mother-hopes-to-keep-daughters-spirit-alive-by-donating-her-organs/2158684>
19. <http://news.bbc.co.uk/1/hi/uk/4003063.stm>
20. <http://fleshandblood.org/story/angela/>
21. <http://www.medicaldaily.com/danish-teen-wakes-dead-just-doctors-prepare-harvest-her-organs-243163>
22. <http://www.dailymail.co.uk/news/article-2219085/Carina-Melchior-The-girl-wouldnt-die-Miracle-Danish-girl-woke-doctors-prepared-organs-donated.html>
23. Methodist Prayer Handbook 2013/14, p8
24. <http://www.independent.co.uk/life-style/health-and-families/health-news/give-organ-donors-transplant-priority-doctor-calls-for-new-way-of-dealing-with-the-problem-of-free-riders-8777115.html>

Images on Pages 1, 3, 5, 10, 15, 19, 20 © Thinkstock 2014

Image on Page 6 © fleshandblood.org 2014

Scripture quotations are from the New Revised Standard Version Bible, copyright © 1989
the Division of Christian Education of the National Council of the Churches of Christ in the United States of America.
Used by permission. All rights reserved.

**You can download this discussion resource free at
www.jointpublicissues.org.uk/organdonation**

Thanks to all those who contributed their time and expertise to producing this resource.

Please send any questions, comments or other feedback to:

The Joint Public Issues Team: Baptist, Methodist and United Reformed Churches working together
25 Marylebone Rd
London NW1 5JR
enquiries@jointpublicissues.org.uk
020 7916 8632

www.jointpublicissues.org.uk
[@publicissues](https://twitter.com/publicissues)
www.facebook.com/jointpublicissues

June 2014

**joint
public
issues
team**

Baptist, Methodist
and United Reformed
Churches working together