

# Organ and Tissue Donation and Transplantation

## People's views

Easy Read

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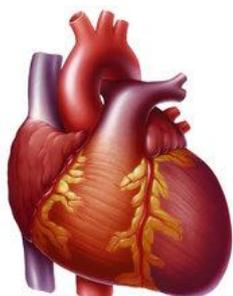
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# What people think of Organ and Tissue Donation and Transplantation

## Part 1 - Summary



The Scottish Government spoke to people about organ and tissue donations and transplants.



Organ is another word for body parts like your heart, liver, kidneys or lungs.

Tissue is another word to describe your bones, muscle or skin.



Donating is another word for giving.

If you donate your organs you can help a sick person get better.

You would then be called an organ donor.



A transplant is a type of surgery. It is where an organ is taken from one person's body and put into the body of another person.



A very small number of people will become organ donors – less than 1%. This means that less than 1 out of every 100 people will become a donor.

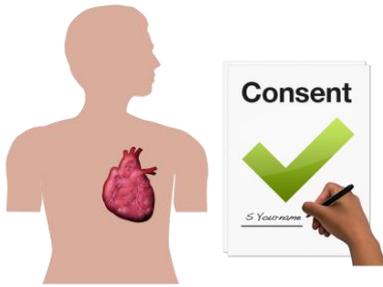
This is because normally it is only possible to donate your organs if you die in intensive care in hospital.



This means there are very small numbers of possible organ donors in Scotland at any time.



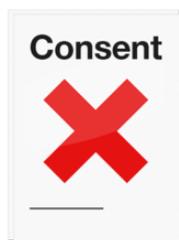
The Scottish Government wanted to know how to get more people to agree to give their organs to someone who needs them after they have died.



The Scottish Government wanted to test a new idea. The old way of doing things was that a person, or their family had to say yes before their organs could be used when they died.



The new idea is that more people could become an organ donor when they die, unless they have already said no.



You can choose not to be an organ donor. You can fill in a form to say no or tell your family or friends that you don't want to.



The Scottish Government wanted to hear what people thought of the new idea. It asked an organisation called the Scottish Health Council to help.

The Scottish Health Council helps to improve care for the people of Scotland.



The Scottish Health Council organised five groups in different parts of Scotland.

NHS Ayrshire & Arran and NHS Forth Valley spoke to young people.

NHS Greater Glasgow and Clyde and NHS Fife spoke to adults with a learning disability.



The groups found that they also needed to talk to young people who were looked after.

That means children who are looked after by people who are not their parents. This could be children who may be in foster care or live in special schools or units.



47 people were in the groups, including people with learning disabilities, young and looked after young people.



The groups agreed that being an organ donor was a good thing unless you say you do not want to.

They thought most people would be happy to do it.



They also thought that in the new system the age that someone could give their organs was 15 or 16 years old, unless they have said no.



People with learning disabilities said it was important to use the right words to explain the process so they would understand.

It was also important for people with learning disabilities to be supported to understand the information, so they can take the time needed to make their own decisions.

They could ask for help from family or if there were no family, then a close friend could help.



All the groups agreed it would be important to be able to change your mind about giving your organs if you wanted to.



Information about the changes to the law would have to be advertised through letters and social media.



The looked after young people said they wanted people they knew from the council to allow organ donation if they had parental rights over the child.

## Part 2 - Background



Organ donation is something special because it can give someone who is unwell the chance of a more-healthy life.

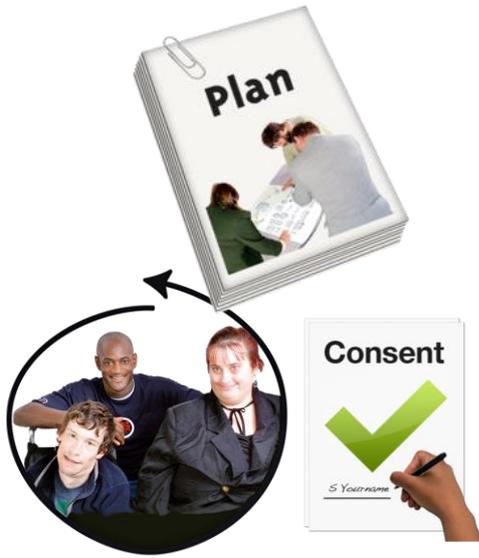


The Scottish Government wants more people to give their organs when they die.

Its plan is to change the law so that more people may become an organ donor when they die, unless they have already said no.



The Scottish Government spoke to different people, including looked after children and people with learning disabilities.



After the four groups told the Scottish Government what they thought, the Government wants to go ahead with the plan.

This means more people may become a donor unless they say they do not want to.

## Part 3 - Getting Feedback



The Scottish Health Council thought the best way to gather views on organ donation was to talk to people and hear their views.

Lots of different groups were involved in the discussions, including:



- Arran Youth Foundation – a charity working with young people.
- Balfron High School
- People First (Scotland) – is the Disabled People’s Organisation led by people with learning disabilities.
- Barnardo’s Scotland – a charity working with disadvantaged young people.

47 people took part in the discussions:



- 13 were people who have a learning disability
- 22 were young people
- 12 were looked after young people



There was also an online survey for looked after young people.

Barnardo's helped organise it.

10 looked after young people did the online survey.

## Part 4 – Feedback from the Group Discussions

This part of the document shows what the discussion groups talked about.



There are some quotes.

This is when we show what someone said.

The quotes will be in “**bold**” so you know that’s what someone said.



People were asked what they thought of organ donation. Most people said it was very important. Someone said, “**It could give someone else a chance.**”



But some people with learning disabilities found the information hard to understand.

They said it was important to “**use the right words**” and “**symbols and pictures make it easier.**”

It is important that people with learning disabilities have support to understand all the information.

The groups then tested the new idea that more people might become organ donors when they die.



Most people thought this was a good idea.

People said it was “**positive and worthwhile**”.

People said that most people would be happy to be a donor, but maybe some people might not get round to signing up.



People said there should still be a way of saying no, if you do not want to be a donor.



And you should be able to change your mind if you want to.



One group was worried that if this new plan goes ahead, it would feel like the Scottish Government were “**forcing**” or making people be donors.



That is why it is important that the Scottish Government has to “**use the right words**” to explain the process.

There should also be “**safeguards**” – this means checks to make sure people understand what they are agreeing to.



People thought it was important to be able to talk to family members and friends about it.



In a group with people with learning disabilities pictures were used to tell a story about a girl called Molly who was thinking about being a donor.

The pictures helped people understand what was happening.



The discussions also talked about what age people should be when they say yes to giving their organs, or no, they do not want to.

Some people said that age 12 was too young to understand the new system.

Someone said, **“Organ donation is not something young teens think about.”**

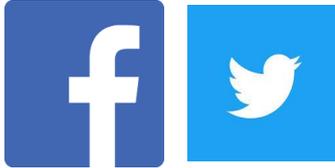


The groups agreed that age 15 or 16 was right. At this age, young people are sitting exams and making other big life decisions.

But, people said it was still important to talk to mums, dads and carers before deciding, then they would know what you wanted to do.



The groups talked about how people could find out about the new law.



Social media was important, and on TV and radio.



Using schools to talk about the new plan in assembly or in class is a good idea.



Posters and leaflets were a good way of sharing information.

These should be in places like toilets and dining areas, so they are seen.

**“Make posters and adverts eye catching and put them in obvious places.”**



Someone said when people turn 16 and get a National Insurance Number, they should also get a letter.



This would explain the changes under the new opt out system.

## Part 5 – Feedback from looked after young people



Four looked after young people talked about organ donation. This is a summary of what they said.

One person did not want to be a donor or for their family members to be donors.



Another person was worried that if they were ill, the doctor might not save them, so that they could use their organs.

This would not happen.

Everyone else thought organ donation was a good idea and said it could save lives.



These young people were worried that people might not know they have to say no, if they do not want their organs donated.

**They wanted to make sure that “people are fully informed on changes in the law, so they can think about their wishes and talk to someone about how they feel.”**



Looked after children sometimes don't have a family. They are looked after by a foster carer, or by the local authority.



The group said that if there was family, they should help decide on organ donation.

If there was no family, then the foster family could decide.



If there was no family, then the local authority could decide.



Some of the looked after young people gave these suggestions for telling people about the new law on organ donation:

- A letter from the Government or your GP
- Information in schools – like presentations
- Advertising and posters, on buses, in toilets, on billboards, in social work offices
- Key workers sharing information
- Social media, like Facebook
- Free telephone helpline for more information



Looked after young people also said what would not work:

- Adverts on YouTube
- Adverts at the cinema
- Stalls with leaflets

**“Don’t set up stalls or hand out leaflets at concerts or festivals.”**



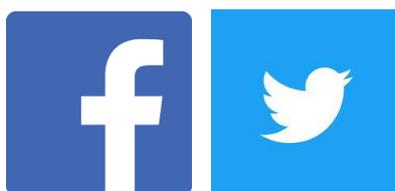
10 looked after young people did an online survey.

They were asked ‘should everyone be a donor unless they choose to opt out?’

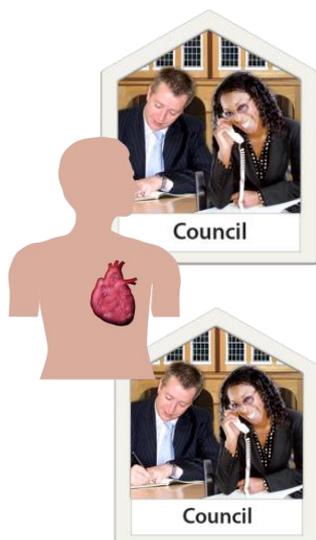
Six people said yes, that was a good idea.

Three people said it was not a good idea and one person was not sure.

**“It is okay to opt out.”**



Social media was the best way to keep up to date, and others thought a letter would be good, so would radio and TV adverts.



Most looked after young people said that if the local authority has responsibility for the young person, then the local authority can make a decision.

If the local authority can contact the person’s family to ask what they think, they should do that too.

## Part 6 - What happens next?



All the comments from the groups and the survey have been shared with the Scottish Government.

This will help them with their new plan.



The Scottish Health Council wanted to say thank you to everyone who took part in a group or did the survey online.



Everyone will get feedback on how they helped and what will happen next.