TIME TO TALK ABOUT ORGAN DONATION

Campaign action pack

WWW.THEWI.ORG.UK
#WITIMETOTALK
TIME TO TALK ABOUT
ORGAN DONATION

WWW.THEWI.ORG.UK
#WITIMETOTALK
The NFWI notes that three people die every day whilst waiting for an organ transplant. We call on every member of the WI to make their wishes regarding organ donation known, and to encourage their families and friends, and members of their local communities to do likewise.

Standon & Cotes Heath WI, Staffordshire federation*
2014 NFWI resolution

We’re encouraging members to talk about organ donation with their loved ones, to make sure that our families can respect our wishes. Families in every part of the UK have a part to play in the transplant process – life saving transplants can only happen with your family’s consent.

Talking about organ donation can be difficult; many of us who want to be donors have never discussed our donation wishes with anyone else.

Research shows that families who are aware that their loved one wanted to be a donor are much more likely to allow donation to take place. Knowing what a loved one wanted eases the burden of the decision at what can be a very distressing time. Letting your family know your wishes – whatever your decision – means that that they can be respected if the situation ever arises. Don’t leave them guessing.

Things to keep in mind
• Whether or not you want to be an organ (and tissue) donor after you die is a very personal choice, but after you pass away the final decision will lie with your loved ones.
• Families in all parts of the UK play a role in the donation process – this includes Wales with the new consent system from December 2015.
• The overall family consent rate in the UK was just under 60% in 2013-14. This is one of the lowest rates in Europe. NHS Blood and Transplant hope to increase this rate to 80% by 2020. Members can play an important role supporting this work. If we had achieved that rate last year, over 1,000 more transplants would have taken place.

Why is talking with your family about organ donation important?
Deciding to be an organ donor is a matter of personal conscience and this WI campaign is focused on making sure members’ wishes are known to their families, whatever they are, so they can be honoured if ever the time comes.

Just under half of all UK citizens have never spoken about organ donation with anyone.

Last year 3,247 families were asked about donating their loved-one’s organs. In the midst of grief and distress, they faced this enormous decision. Many families found the courage to say yes. But just over 40% of them decided not to let organ donation go ahead. The biggest group of these families - 221 - who did not allow donation to go ahead last year said that they knew their loved-one did not want to be a donor. But another 189 families said their reason was because they didn’t know what their loved one wanted to do.

The decision to be an organ donor for around two thirds of all transplants last year came from the deceased’s family; in the region of just 40% of organ donors were on the NHS Organ Donor Register (ODR).

We know that when someone dies, they are much more likely to go on to donate their organs if their name is on the ODR and if their wishes are known by their family. The family consent rate last year was just under 60%. If the patient was on the ODR or if the patient’s wishes were known, it was almost as high as 90%. In short, if you want to be a donor, you simply MUST tell someone close to you. Don’t leave the burden of your personal decision to family members – make a decision today and let your loved-ones know what you want.
“We hope everyone in the UK will be proud to donate their organs, when and if they can. But we know this won't happen without some inspirational leadership. We are asking you to provide this leadership: to talk to your families, your friends and your communities so that no family is left to guess what their loved one wanted.”

Sally Johnson, NHS Blood and Transplant, NFWI Annual Meeting

Did you know?

If you're not sure about becoming a donor, here are some interesting facts about organ donation to help you make a choice.

Age isn’t a barrier to donation; well over half of donors were over 50 last year and growing numbers are in their 80s!

The average age of a cornea donor is 67, while the average age of a cornea recipient is 61.

Transplants are the most effective treatment for organ failure.

The NHS Organ Donor Register now holds more than 20 million names. Of those not already on the ODR, 45% say they are willing to join ‘right now’.

Medical conditions may not prevent you from being a donor. 40% of lungs donated come from those who have smoked. New research suggests a patient’s chance of survival is higher if they receive lungs from donors with a smoking history, than if they remain on the waiting list for a transplant from a donor with no history of smoking.

40% of people in Scotland are on the ODR, but only 33% of Welsh people, and only 32% of English people.

Whilst more women are registered donors overall (54% of registrants), men are overrepresented amongst those over 50.

Health professionals have a duty of care to try to save a life first. If, despite all their efforts, the patient dies, their wish to be an organ donor may then be fulfilled.
Recent advances
In 2008 the Organ Donation Taskforce set a goal: to increase the number of deceased organ donors by 50% within five years. This was achieved, and in 2013 the NHS set out new plans focussed on boosting the number of families allowing donation to go ahead. The aim is to achieve ‘a revolution in consent’ whereby family consent rates will increase to 80% by 2020. In recent years consent rates have remained stable, at just under 60%. More families have given their consent, but that is because more families have been asked, not because they have been more likely to say yes.

At the same time, the NHS faces demographic challenges which affect the transplant system like any part of healthcare. Donors are older, and heavier, which means the average donor today can donate fewer organs than donors of previous decades. Further, the number of potential donors is also declining. People are living longer and fewer are dying in hospitals in circumstances where they can be organ donors.

Wales’ new consent system
This resolution is important in Wales. The Welsh government has decided to implement a ‘soft’ opt-out system of organ donation. This means that every Welsh resident is deemed to have given their consent to donate their organs upon their death, unless they opt-out. The role of families however, will remain the same as under the current system. Families will still have the right to prevent donation of organs, even if an individual has done nothing and their consent is ‘deemed’. They also still have to be consulted when someone has opted into donating their organs (called ‘express’ consent). These allowances have been made to ensure families are not distressed, and to help doctors know more about the life of the person donating.

There are 200 people on the waiting list for an organ in Wales. The Welsh Government’s view is that a 25% increase in the donation rate is possible with a change to the consent system. But family and wider societal attitudes to donation will still be crucial for improving transplant rates in Wales when the new system comes into force on 1 December 2015. The Welsh Government has launched a public information campaign on the new consent system and the importance of making your wishes known to your loved ones. You can read more at www.organdonationwales.org

Organ transplants save the NHS £316m each year and improve the quality and length of patients’ lives.

How can I talk to my loved ones about my Organ Donation wishes?
We know that talking about organ donation is difficult. Over 90% of us would take an organ and 65% of us are willing to be organ donors, but many of us who want to be donors have never talked about donation with anyone. Even a third of people who are registered organ donors haven’t told anyone about their decision.

For those of you that would like to donate don’t let obstacles like your busy lifestyle stop you sharing your wishes. Find the Time to Talk!

• Do you donate blood? Tell your loved one and then ask about organ donation…
• Do you have a will? If you’re in the process of writing or updating yours, use it as a conversation starter to talk about your organ donation wishes…
• Are you going on holiday to Spain this year? It has the best family consent rates in Europe! We could learn a thing or two. Get your travel insurance and your family conversations sorted before you travel…
• Share an inspiring organ donation story with your loved one. At the Annual Meeting in Leeds this year one member said she could only see the stage because someone had donated corneas so her sight was restored. And the member who said how comforted her family had been to help others on the transplant waiting list by donating the organs of her daughter; ensuring something positive came out of a tragic loss. Talk about the AM to your loved one and go from there….
**Time to Talk about Organ Donation**

**Campaign action pack**

---

## Three ways to take action

### 1 Join the Time to Talk campaign ‘Big Conversation’

- Every single discussion about organ donation is part of a bigger conversation. We’re calling on members to take part in this conversation by bringing the WI’s craft and campaigning strengths together.

- Let us know who you’ve told about your organ donation decision by illustrating or crafting their name and take a photograph of your creation.

- You might have had the conversation at the beach; spell out your loved one’s name in sand or stones; or over a cup of tea; why not decorate a teacup or bake something with your loved one’s name to show the slice of cake you shared whilst talking; or keep it simple with a ‘selfie’ spelling out who you shared your donation decision with.

- Send your photographs to the Public Affairs Department by post, email or via social media with the hashtag #WITimetoTalk. We hope thousands of members will take part. We’ll share the results online during the next year and in a special exhibition as part of the NFWI’s centenary celebrations in 2015. A step by step guide to the Big Conversation project is available from the Public Affairs team.

### 2 Raise awareness of the Time to Talk campaign

- Put a Time to Talk campaign poster up in your local library or GP’s surgery.

- Request Organ Donation Registration leaflets from the WI and ask your local library or GP’s surgery if you can leave them there.

- Set up a stall at a local fete to inform the public about how important family conversations about organ donation are.

- Why not invite a local transplant charity or local hospital speaker to give a talk to your WI. Or use one of the Time to Talk presentations that are available on the WI’s website to deliver a talk about the campaign to your local WI or other community groups.

### 3 Get online

- Tweet and help promote the campaign! Use the hashtag #WITimetoTalk

- Follow us on Twitter @womensinstitute, like us on Facebook www.facebook.com/wi

- Like and share our infographics and blog posts on your own Facebook page or social media channels.

---

**Contact us**

National Federation of Women’s Institutes
Public Affairs Department
104 New Kings Road, London. SW6 4LY
Tel: 020 7371 9300 ext 212
www.theWI.org.uk
publicaffairs@nfwi.org.uk

NFWI-Wales
19 Cathedral Road, Cardiff, CF11 9HA
Tel: 02920 221 712

Incorporated in England & Wales as a company Limited by Guarantee – No. 251 7690
Charity Registration No. 803793

August 2014

*Please note that this is the correct wording of the resolution, an unfortunate error was made in the paperwork that was circulated in the June 2014 mailing.*