

# **Organ Donation: Saving Lives in Black and Asian Communities**



**A toolkit for Members of Parliament**  
**October 2018**

## Surinder Kaur Jagdev saved 5 people



In 2009 Surinder Kaur Jagdev, a healthy 60-year-old, suffered a sudden brain haemorrhage after a fall. Five of her organs and tissues were donated.

Her daughter, Manjinder (featured above) received a call from her father and brother to say her mother had fallen and was on the way to the hospital. On arrival doctors told the family that due to the type of haemorrhage she had, she was likely to have another. The next day Surinder had a second haemorrhage and the family were told that nothing more could be done.

Surinder was a devout Sikh lady and the family felt that because in life she was such a giving person, in death she would have wanted to be also. The family decided to donate 5 organs as 5 is a significant number in the Sikh faith. Surinder's family also donated her corneas as they felt that she would have liked the idea of giving someone the gift of sight.



**We need more  
Black and Asian  
donors**

**Organ donation is a precious gift. One donor could potentially save or transform up to 9 lives through organ donation. But we need more Black and Asian donors.**

**We hope that this toolkit can help you to promote organ donation to communities in your constituency and to build their trust that organ donation is only ever considered once doctors have done everything they can to save a patient's life and that the donation process is reliable, fair and respects an individual's wishes.**

### **Who is NHS Blood and Transplant?**

We stand for hope. We stand for life. We help people do something extraordinary - donate blood, organs, tissues or stem cells to save someone in need. NHS Blood and Transplant is a Special Health Authority. We save and improve lives by providing a safe, reliable and efficient supply of blood to the NHS in England and we are the organ donor organisation for the UK. We rely on thousands of members of the public who voluntarily donate their blood, organs, tissues and stem cells. However, we face significant challenges in encouraging people from Black and Asian and Minority Ethnic (BAME) communities to donate organs.

### **Why we need more donors from BAME communities**

BAME patients make up a third of the active kidney transplant waiting list. Generally, these patients wait significantly longer for a kidney transplant than white patients if they are fortunate enough to receive an organ from a donor. Sadly, many will die waiting.

Black and Asian people are more likely to develop conditions such as high blood pressure, diabetes and certain forms of hepatitis than white people. This makes them more likely to need a transplant.

Organ donation is done anonymously with a donor's organs going to patients who are well matched.

Although many BAME patients can receive a transplant from a white donor, for many the best match will come from a donor from the same ethnic background.

While some people with a BAME background go on to donate when they die each year, this is not enough to meet the needs of all patients waiting for a transplant from those communities.

Only 7 out of every 100 people who have signed up to the NHS Organ Donor Register and told us their ethnicity are from BAME communities. These groups are also much less likely to consent to donating a relative's organs.

More information about organ donation and ethnicity is available here: [bit.ly/odtandethnicity](https://bit.ly/odtandethnicity)

## **Why it's important to talk about organ donation**

Many people believe that all you need to do to show you want to be an organ donor is to join the NHS Organ Donor Register or carry a donor card. However, if you die in circumstances where you could become an organ donor your family would be approached by a specialist nurse and asked to support your decision to donate.

It can be a big burden for families to make such an important decision at a difficult time, especially if they are unaware of what the individual wanted.

We know that 8 out of 10 people support organ donation. But around half of all adults in England have never talked to anyone about their wishes.

Fewer than half (47%) of families agree to donation going ahead if they are unaware of their loved one's decision to be a donor. This rises to almost 9 out of 10 when the decision to be an organ donor is known.

If your family doesn't know your decision they may not support it. Even if you are on the NHS Organ Donor Register we will ask your family for their support before organ donation goes ahead.

If the person had not recorded a decision to donate, then NHS Blood and Transplant's specially trained nurses sensitively provide information to their family to help them to make the decision on behalf of their relative.

When a family says no to organ donation, someone waiting for a transplant may miss out on their only opportunity for a transplant which could save their life.

Save your family from having to guess what you would have wanted, by making sure they know if you want to be a donor. We have some tips on our website to help you get talking to your loved ones about organ donation: [bit.ly/mpodtconv](https://bit.ly/mpodtconv)

## Myth Busting

Here are some common misconceptions about organ donation

### Organ donation is against my religion

The major religions in the UK support the idea of organ donation and transplantation. These religions include Christianity, Islam, Judaism, Buddhism, Hinduism and Sikhism.

From December 2018, there will be the opportunity for people registering online as organ donors to record within their registration that they would like NHS staff to speak to their family and anyone else appropriate about how organ donation can go ahead in line with their faith or beliefs.

If someone is unsure of their faith's position on donation, they can ask their religious leader or teacher. There is more information about religion and organ donation on our website: [bit.ly/odreligion](http://bit.ly/odreligion)

### There are enough organ donors

Around three people die every day across the United Kingdom in need of a life-saving organ transplant.

Only 1 in 100 people across the UK die in circumstances where their organs can be considered for transplantation. This means every potential donor is of vital importance. If more people join the NHS Organ Donor Register and talk to their families and ask them to support their decision to be a donor, more lives will be saved, as more families will agree to support their loved one's decision to donate.

### Donation will leave my body disfigured and prevent me having an open-casket funeral

The donor is treated with the utmost care and respect during the removal of organs and/or tissue for donation. Specialist healthcare professionals will make sure you are treated with dignity and respect. We carefully close and cover the surgical incision after donation as in any other surgical procedure. The arrangements for a viewing of a loved one's body after donation are the same as after a death where donation doesn't take place.

Organ and tissue donation doesn't stop people from having an open-casket funeral. The body is clothed for burial, so there are no visible signs of organ or tissue donation.

### You need a donor card to donate in England

An Organ Donor Card is a great way to show you're committed to saving lives. However, you don't need to carry an organ donor card for your organs to be donated, as medical staff will always consult the NHS Organ Donor Register and speak to your family.

## Organs that aren't used in the UK are sold abroad

In the UK, organs will only be retrieved if a transplant centre expects to use them for one of their patients. If at the last minute the centre decides the organ is unsuitable for the intended patient, it will be offered to another patient in the UK. If there are no suitable UK patients (which is very rare) then it may be offered free of charge to other European Centres. European centres also send surplus organs to the UK. UK organs are never sold either at home or abroad and any attempt to do so would be illegal.

There are more myth busting questions available at: [bit.ly/prodonhub](http://bit.ly/prodonhub)

## Could you be a living donor?

Living donation is when someone donates one of their organs – usually a kidney - to someone else, whilst they are still alive. Most of us can live perfectly well with only one kidney, and yet nearly all of us have two.

Most often living donors are close relatives or friend of the recipient, but you can still donate an organ to someone you do not know.

You can also donate part of your liver. For more information visit: [bit.ly/livdon](http://bit.ly/livdon)

## Help to spread the message

We have images they can easily be shared on social media, animations and website banners that you can share. Download them from [bit.ly/prodonmat](http://bit.ly/prodonmat)

## Constituency statistics

Find out the number of people on the Organ Donor Register, the number of people on the transplant waiting list and number of donors for your constituency:

[bit.ly/odtconstats](http://bit.ly/odtconstats)

## Blood Donation

We are also responsible for blood donation in England. We need donors from all communities and ethnic backgrounds to donate blood so we can meet the needs of all patients in England now and in the years to come. Black, Asian and minority ethnic donors are specifically needed because:

- some patients who receive frequent blood transfusions need blood to be closely matched to their own.
- the best match typically comes from blood donors from the same ethnic background.

- sickle cell disease which is treated through blood transfusions, most commonly affects black people.
- blood subtype Ro, is needed for treating sickle cell disease and is more common in black donors.
- We urgently need more black donors to meet the needs of sickle cell patients.

For more information visit: [www.blood.co.uk](http://www.blood.co.uk)

## Other ways you can support organ donation

**Have you joined the NHS Organ Donor Register?** It only takes a couple of minutes to join the register at [bit.ly/odrreg](http://bit.ly/odrreg). When you receive your organ donor card why not tweet a selfie with your new card.

**Want to meet the chair of your local Organ Donation Committee?** Most hospitals have an Organ Donation Committee - a group of clinical professionals and volunteers who work to maximise the overall number of organs donated through better support for potential donors and their families. We can set up a meeting with the Chair of your local Organ Donation Committee so they can talk to you in more detail about their work. Contact our External Affairs team to arrange – [externalaffairs@nhsbt.nhs.uk](mailto:externalaffairs@nhsbt.nhs.uk)

**Are there any big community events where we could promote donation?** We can provide speakers, banner stands and materials to any public events that you would like to invite NHS Blood and Transplant staff to attend. Contact our External Affairs team to arrange – [externalaffairs@nhsbt.nhs.uk](mailto:externalaffairs@nhsbt.nhs.uk)

**Would you like to organise a local summit meeting?** We can help you to organise a summit meeting with local faith and community leaders to discuss how we can promote donation in your constituency. Contact our External Affairs team to arrange – [externalaffairs@nhsbt.nhs.uk](mailto:externalaffairs@nhsbt.nhs.uk)

**Could you talk to Secondary Schools in your constituency?** We have developed a teaching resource for secondary schools. You can support us by encouraging schools in your constituency to use our lesson plans. More information at [bit.ly/pdhteachres](http://bit.ly/pdhteachres)

**Can you display our leaflet in your office?** You can order a supply of leaflets from our website: [bit.ly/odtleaflets](http://bit.ly/odtleaflets)

## Further information

Join the NHS Organ Donor Register: [bit.ly/odrreg](https://bit.ly/odrreg)

More information about organ donation and ethnicity: [bit.ly/odtandethnicity](https://bit.ly/odtandethnicity)

Why it's important to have a conversation: [bit.ly/mpodtconv](https://bit.ly/mpodtconv)

Myth Buster: [bit.ly/livdon](https://bit.ly/livdon)

What religions say about organ donation: [bit.ly/odreligion](https://bit.ly/odreligion)

Constituency statistics [bit.ly/odtconstats](https://bit.ly/odtconstats)

Order leaflets: [bit.ly/odtleaflets](https://bit.ly/odtleaflets)

Teaching resources: [bit.ly/pdhteachres](https://bit.ly/pdhteachres)

Digital assets to promote donation: [bit.ly/prodonmat](https://bit.ly/prodonmat)

More information on living donation: [bit.ly/livdon](https://bit.ly/livdon)

## Charities

Team Margot - [teammargot.com](https://teammargot.com)

Kidney Care UK - [kidneycareuk.org](https://kidneycareuk.org)

Kidney Research UK - [kidneyresearchuk.org](https://kidneyresearchuk.org)

National Kidney Federation - [kidney.org.uk](https://kidney.org.uk)

ACLT - [aclt.org](https://aclt.org)

National BAME Transplant Alliance - [nbta-uk.org.uk](https://nbta-uk.org.uk)



## Suggested social media posts



We need more  
Black and Asian  
donors



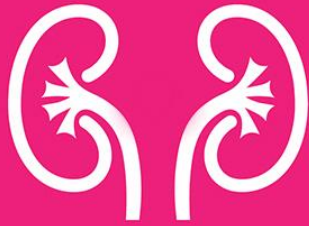
Patients with Black and Asian heritage wait longer for a kidney transplant due to the lack of suitable organs. Join the Organ Donor Register: [bit.ly/2L9FNLM](https://bit.ly/2L9FNLM) #yesidonate



Talk about  
your decision  
with family  
and friends.



If you want to be an organ donor, tell your family. And ask them if they want to be donors too: [bit.ly/2GACTPU](https://bit.ly/2GACTPU) #yesidonate



Around 5,000 people in the UK need a kidney transplant to transform their lives

[organdonation.nhs.uk/livingdonation](http://organdonation.nhs.uk/livingdonation)



Around 5,000 people in the UK need a kidney transplant to transform their lives. Find out more about becoming a living organ donor: [bit.ly/2PLJL9N](http://bit.ly/2PLJL9N) #yesidonate



Could you be a living donor?



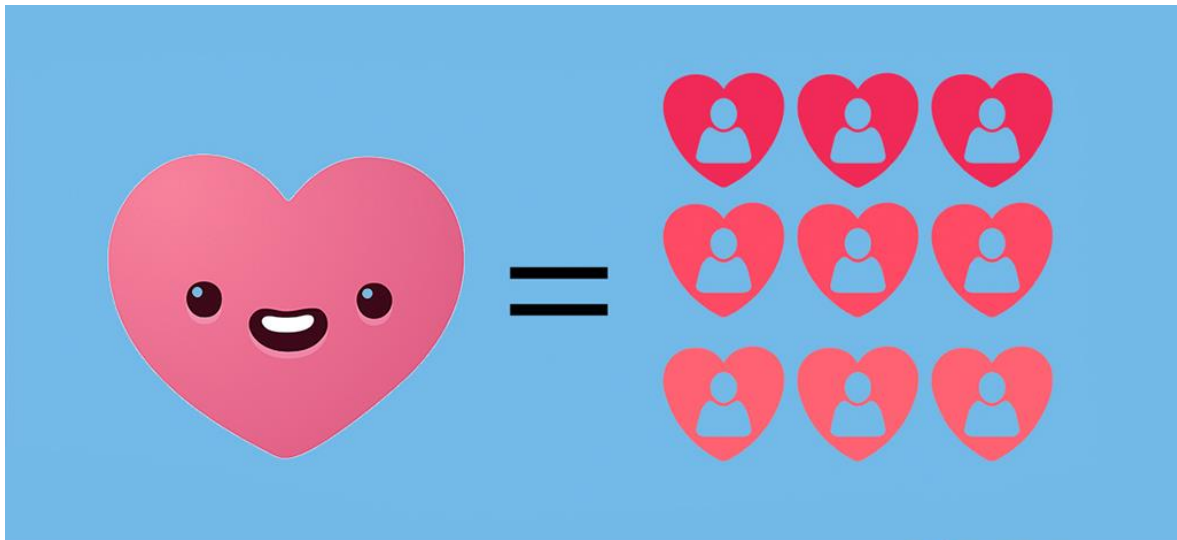
A living donor can donate to someone they know, such as a family member, or someone they don't know. Read more about living donation: [bit.ly/2PNNR9T](http://bit.ly/2PNNR9T) #yesidonate



If you needed an organ transplant, would you have one?



If you needed an organ transplant, would you have one? If so, please help others. Join the Organ Donor Register: [bit.ly/2PQPCR8](https://bit.ly/2PQPCR8) #yesidonate



One donor can save or transform up to 9 lives through organ donation. Join the Organ Donor Register today: [bit.ly/2GCCOTS](https://bit.ly/2GCCOTS) #yesidonate