



Patient Participation Group

## Charlbury Patient Participation Group Newsletter Issue No.9 July 2020

### CHARLBURY MEDICAL PRACTICE PATIENT PARTICIPATION GROUP

This is the summer newsletter from Charlbury Patient Participation Group (CPPG) for all patients of the practice. The impact of coronavirus in our lives continues to be significant and the future is still uncertain.

The Practice Manager of Charlbury Medical Centre thanks all the patients who have shown patience and understanding over the last four months. Patients have adapted to new ways of contacting the medical centre and consulting GPs and nurses. The newly installed telephone system is working well. There are now sufficient telephone lines to enable telephone consultations to be held without occupying all the outside lines. The queuing system lets us know where we are in the queue, the system recognises our phone number and brings up the patient record for the receptionist to see. We hope this will lead to a more efficient service which benefits both patients and staff.

You might like to consider using *econsult* as a way of contacting the Practice. Information and access are on the home page of the medical centre website. The name of the provider of this service may change over the next few weeks, but the service will still be available. Please *do not email* the medical centre with health concerns using the general email, this email account is not checked frequently.

In this issue we look at:

- Recently published symptoms which may indicate infection with the coronavirus; 7 precautions to take to try to prevent further outbreaks of the virus.
- The development of possible vaccines at The Jenner Institute, Oxford, and Imperial College London, pages 4 to 7.
- Diabetes, a disease whose presence can significantly affect the impact of the coronavirus. What is diabetes? What are the symptoms? A personal story from a Charlbury person about their efforts to keep diabetes at bay is on page 10.
- Organ donation. The law changed on 20 May 2020. We are now all potential donors, unless we are in the small group of people who are deemed unable to become donors, or we take steps to opt out of the system. On page 15, we share Helen's story of live organ donation from a mother to her son.

We have posted information from the medical centre and from reliable sources throughout the pandemic about the coronavirus, its impact on hospital services and much more on the Charlbury town website where it is found usually under the heading "News", then moved to the patient group page which is found by clicking on Community > Health and Wellbeing > CPPG. We are trying to make it simpler!

## Coronavirus News

As lockdown begins to lift in the UK, it's more important than ever to take precautions to stay safe and prevent new outbreaks of COVID-19.

The COVID-19 Symptom Study app has been developed by health science company ZOE and it is endorsed by the Welsh Government, NHS Wales, the Scottish Government and NHS Scotland. 3,995,459 participants have downloaded the app and are using it to regularly report on their health, making it the largest public science project of its kind anywhere in the world. App data is being analysed in collaboration with King's College London researchers.

This information is sourced from the App's web pages: <https://covid.joinzoe.com>

### Regular and proper hand washing

At the beginning of the COVID-19 outbreak there was a lot of focus on hand washing, and for good reason. Hand washing is one of the easiest ways we can protect ourselves and others from COVID-19. Washing hands thoroughly with soap and hot water removes traces of the virus, stopping us spreading it to the surfaces we touch and also on to our own faces and mouths.

Basic personal hygiene like this is even more important right now if we want to prevent unnecessary spread of COVID-19 and another resurgence of the virus in the population. For more information about how to wash your hand please visit the NHS website.



How to practice proper hand washing

### 2. Cover your mouth and nose when you can't keep socially distant

Wearing a face covering in public has now become compulsory for people travelling by bus, train, ferry or plane in England, and from 24 July in shops in England (with a few exceptions)

This is a precautionary measure to help slow the transmission of COVID-19 on public transport and in public places. We also recommend wearing a face covering in any situation where you are indoors and can't keep at least 1m from people outside of your family bubble.

For more information about the use of face coverings please visit:

- When and how to use masks (World Health Organization)
- How to wear and make a cloth face covering (Public Health England)

### **3. Avoid public transport where you can**

Public transport due to the proximity and shared surfaces make it a perfect place for viruses to spread so try to avoid using buses, trains and tubes where possible by walking or cycling, and not making any non-essential journeys. With lockdown lifting this might seem like it is unnecessary and restrictive but as we know from the data the virus is still in the population, so limiting public transport will reduce your likelihood of catching the virus and of you spreading it further. Plus, physical activity like cycling and walking more is great for a person's overall health so it's a win-win!

### **4. Be aware of all the symptoms of COVID-19**

The UK Government has only officially stated that there are three symptoms of COVID-19; fever, persistent cough and loss of smell and taste (anosmia). But did you know that according to the research from the COVID Symptom Study we have identified 19 symptoms related to COVID-19? This seems like a lot, but it's important to know all the potential symptoms because if you or someone you know is experiencing any of these it might mean you or they have COVID and therefore need to stay at home.

The most important are those that often occur in the first two days, which can be confused with other causes. These include headache, sore throat and muscle pains. The classical NHS approved symptoms typically occur at days 3-4 although there is wide variation. The vast majority of the users of the symptom app who are unwell are putting up with their symptoms at home without contacting the NHS. If they are temporary, or symptoms you frequently suffer from, maybe due to hay fever etc., they are unlikely to be due to Covid-19. But with any of these symptoms it is safer for everyone to self isolate for a few days and if you are feeling seriously unwell to ask for a test. Some of the symptoms are listed (in rough order of how predictive they are of the disease):

- Loss of smell/taste
- Persistent cough
- Fatigue
- Loss of appetite
- Skin rash
- Hives
- Fever
- Severe muscle pain
- Shortness of breath
- Diarrhoea
- Delirium
- Abdominal pain
- Chest pain

## 5. Test yourself at home

If you are unsure whether or not you have some of these symptoms, there are a few simple ways you can check yourself at home. Things to ask yourself include:

- Can you smell certain cupboard staples like coffee, orange zest or mint? If you struggle to smell these you could be presenting with loss of taste or smell a key symptom of COVID-19.
- Do you have a temperature? You can check yourself by using an at home thermometer or checking how the skin feels to the touch.
- Do you have a rash? One of the early signs of COVID-19 is skin rashes, it's a good idea to check your body daily, particularly your chest or back and your toes.
- Pay attention to symptoms that are very unusual for you. For example if you never get headaches -then it will be more suspicious than if you suffer regularly
- 

## 6. Be aware of how long COVID-19 can last

The data from the app shows us that on average it takes people 10-12 days to start feeling better. And we are seeing a significant number of people reporting symptoms that can go on much longer than this, in some cases for 30 days or more in one in 20 people. Many long term sufferers will relapse with days when they feel well, giving them false hope that they have recovered. The idea that COVID lasts for just a few days and is like flu is misleading, being aware that feeling unwell can last for a long time is important to make sure we aren't expecting ourselves and others to feel better too quickly and encourage people to stay at home until they feel better!

## The Search for a Vaccine

### The search for a vaccine against Covid-19

#### Virus

- Viruses are the most common pieces of biology on the planet. They're designed to invade the cells in other organisms, and while most of them are harmless, some can make us very unwell.

#### Covid-19

- This is the name of the disease that is commonly being referred to as coronavirus, the **virus** that causes the disease Sars-COV-19. It's called this because it's regarded as very close relative to Severe Acute Respiratory Syndrome (SARS-CoV), which saw an outbreak in 2003.

#### Coronavirus

- A generic term to describe a large family of viruses that cause illness, ranging from the common cold to more severe diseases like SARS. They often spread from animals to people.

**What is a vaccine?** A vaccine is something used to stimulate the immune system's response, mimicking an infection. It's a way of encouraging the body to produce an immune response that can protect against a disease, in the way a person might react if they were infected with that disease normally.

Vaccines typically show small amounts of a virus or bacteria to the immune system and the body's defences recognise them as an invader and learn to fight them. If we then catch that virus or bacteria, the body already knows what to do.

The genetic sequence of the virus was discovered and shared by scientists in China. Scientists at the Jenner Institute and Oxford Vaccine Group could then make the vaccine.

The Jenner Institute in Oxford developed a Covid-19 vaccine in January 2020. As scientists working on infectious diseases, they understood a pandemic could happen at any time.

The vaccine was made by adding genetic material – called spike glycoprotein – that is found on the surface of SARS-CoV-2 to an adenoviral vector. (Adenoviral vectors are a very well-studied vaccine type, having been used safely in thousands of subjects, from 1 week to 90 years of age, in vaccines targeting over 10 different diseases).

Researchers have shown that the antibodies produced against sections of the spike protein are able to neutralize (kill) the virus when tested in the laboratory.

By vaccinating volunteers, scientists hope to make the human body recognise and develop an immune response (i.e. develop antibodies) to the spike glycoprotein that will help stop the SARS-CoV-2 virus from entering human cells and causing Covid-19.

The purpose of the Oxford study is to test a new vaccine against COVID-19 in healthy volunteers.

The study aims to assess how well people across a broad range of ages could be protected from COVID-19 with this new vaccine. It will also provide valuable information on safety aspects of the vaccine and its ability to generate good immune responses against the virus.

In the first part of the trial just over 1100 adults participated in having either the Covid-19 vaccine or a different well used and safe vaccine.

The phase II part of the study involves expanding the age range of people the vaccine is assessed in, to include a small number of adults and children:

- Aged 56-69
- Aged over 70
- Aged between 5-12 years

For these groups, researchers are assessing the immune response to the vaccine in people of different ages, to find out if there is variation in how well the immune system responds in older people or children.

The phase III part of the study involves assessing how the vaccine works in a large number of people over the age of 18. This group will allow assessment of how well the vaccine works to prevent people from becoming infected with COVID-19.

In addition to the UK, volunteers in Brazil have begun receiving a trial vaccine against COVID-19, in Latin America's first phase 3 COVID-19 clinical trial.

The trial officially began on Saturday 20th June and will enrol 5,000 volunteers across Brazil.

Source: <https://covid19vaccinetrial.co.uk> and <https://www.jenner.ac.uk>

### **Imperial College London, <https://www.imperial.ac.uk>**

The team at Imperial College London has developed a possible vaccine against Covid-19.

The team has successfully administered 15 doses of the vaccine to healthy volunteers, and will continue to recruit participants for the trial, which will deliver two doses to 300 people in the current phase, with plans for a further trial involving 6,000 people to start in October.

Scientists do not know the level of immunity we need to have to prevent infection which makes it difficult to predict what the chances are for finding a successful vaccine.

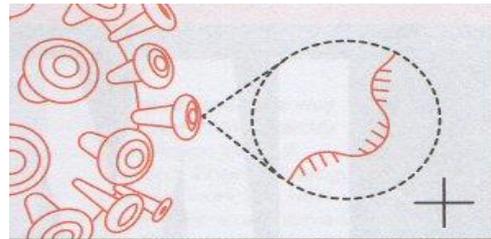
Professor Robin Shattock, heads the team developing the vaccine at Imperial College. This vaccine uses a new idea in vaccine technology which the team has been developing over the past few years. By injecting the vaccine “your muscle becomes the factory which makes the vaccine which triggers your immune system to make protective white cells and antibodies.”, says Professor Shattock.

The illustration on the next page shows how the vaccine was developed.

Source: Imperial/48 – summer 2020

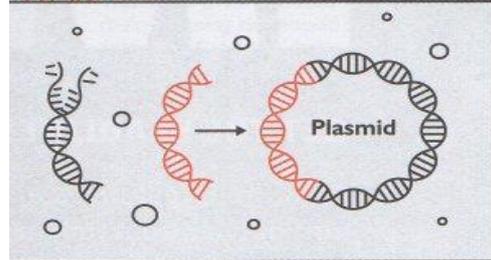
STAGE 1 Within weeks of the first cases of COVID – 19 scientists in China restructured and altered the genetic code of the SARS-CoV-2 virus.

1



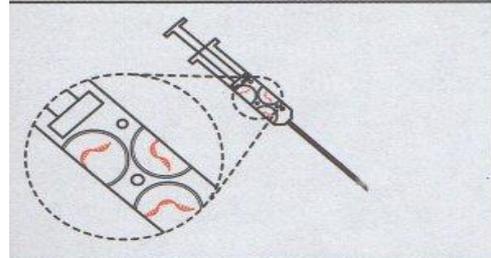
STAGE 2 The Imperial team used this code to produce strands of DNA in the lab – these hold the building instructions for ‘spike’ proteins on the outside of the virus. The DNA is built into loops of genetic material (called plasmids) to produce copies of the self-amplifying RNA.

2



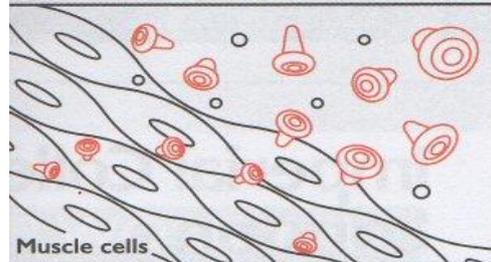
STAGE 3 The final vaccine is delivered as RNA strands in liquid droplets. To check if the vaccine is safe and effective the team first needs to see if it produces an immune response in animals

3



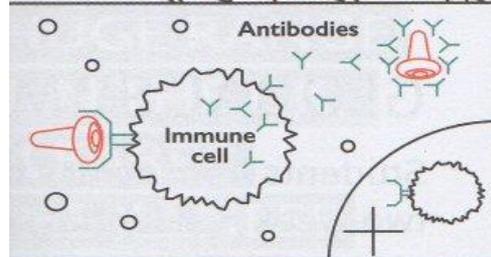
STAGE 4 The vaccine can ‘amplify’ itself inside the body, meaning it makes copies of the instructions it contains (in the form of RNA). Once injected into muscle the cells should produce copies of the coronavirus protein, which will be picked up by the body’s immune system as a threat.

4



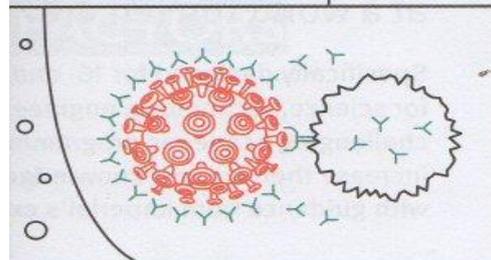
STAGE 5 When immune cells come across these proteins they by creating antibodies to fight off the danger. But they also create a lasting memory of the treat for any future attack.

5



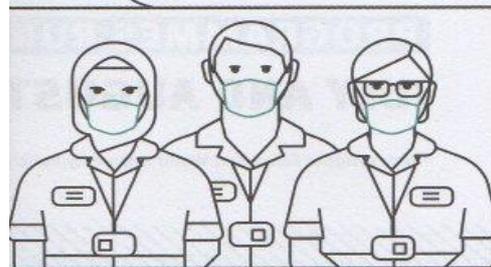
STAGE 6 The hope is that the vaccine will train people’s immune systems to recognise and defend against SARS-CoV-2. If they come into contact with the virus in the future they should be ready to fight it off, giving them some protection against COVID – 19.

6



STAGE 7 Having an effective vaccine would enable us to protect the frontline health workers who are dealing with patients. But it could also be extended to the general population.

7



**According to Diabetes Uk someone is diagnosed with diabetes every 2 minutes.**

**There are two main types of diabetes, Type 1 and Type 2. About 90% of people with diabetes have Type 2, about 8% have Type 1.**

If someone has either Type 1 or Type 2 diabetes, it means they have too much glucose (a type of sugar) in the blood. This is the same for both types. But the difference between them is how this happens.

Type 1 diabetes is an auto-immune condition. This means the body has attacked and destroyed the cells that make insulin, so the body can't make insulin anymore.

We all need insulin as it helps take the glucose from our blood into our body's cells. We then use this glucose for energy. Without insulin, the glucose level in the blood gets too high.

### **What is Type 2 diabetes?**

**Type 2 diabetes is a serious condition where a hormone called insulin can't work properly, or the pancreas which makes insulin, can't make enough of it.**

### **What are the causes of Type 2 diabetes?**

We all need insulin to live. It does an essential job. It allows the glucose in our blood to enter our cells and fuel our bodies. When a person has Type 2 diabetes, the body still breaks down carbohydrate from food and drink and turns it into glucose.

The pancreas responds to this by releasing insulin. But because this insulin can't work properly, blood glucose (also called sugar) levels keep rising. More insulin is released. For some people with Type 2 diabetes this can eventually tire the pancreas out, meaning their body makes less and less insulin. This causes even higher blood sugar levels.

Without treatment, and over a long period of time, high sugar levels in the blood can seriously damage the heart, eyes, feet and kidneys.

### **Risk factors for Type 2 diabetes**

Some things put people at more risk:

- family history
- ethnic background
- age
- being overweight or obese.

Type 2 diabetes develops more slowly, especially in the early stages which makes it harder to spot the symptoms, and can go unrecognised by the person for many years.

We also know that there are things we can do to reduce the risk of developing Type 2 diabetes. Things like eating healthily, being active and maintaining a healthy weight can help to prevent Type 2.

People are more likely to get Type 2 if over 40 years of age, or if they are South Asian, over 25 years of age.

But Type 2 is also becoming more common in younger people. More and more children and young people get diagnosed with Type 2 in the UK each year.

## Type 1 diabetes

A big difference between the two types is that Type 1 isn't affected by lifestyle, or weight. That means the risk of developing Type 1 can't be affected by lifestyle changes.

People up to the age of 40 are more likely to be diagnosed with Type 1, especially children. In fact, most children with diabetes have Type 1. But, although it's less common, people over 40 can also be diagnosed with it. The symptoms of Type 1 diabetes can appear quite quickly which make them harder to ignore.

## Symptoms of Type 1 and Type 2

Type 1 and Type 2 diabetes share common symptoms. They are:

- going to the toilet a lot, especially at night
- being really thirsty
- feeling more tired than usual
- losing weight without trying to
- genital itching or thrush
- cuts and wounds take longer to heal
- blurred vision.

If you have any of symptoms of diabetes, contact your GP.

It doesn't necessarily mean you have diabetes, but it's worth checking – early diagnosis, treatment and good control are vital for good health and reduce the chances of developing serious complications.

The Diabetes UK website has useful accurate and up to date information:  
[www.diabetes.org.uk](http://www.diabetes.org.uk) To talk to an advisor, ring: **0345 123 2399**

**Please**, if you have any of symptoms of diabetes, contact your GP. If in doubt, find out.

**On a positive note a Charlbury patient shares his experiences of how to avoid Type 2 Diabetes. Read his story on the next page.**



"It wasn't really insulin. You don't have diabetes yet. It was just a warning shot."

*'On 11<sup>th</sup> March 2020 at 10:15 am, I had such a severe attack of giddiness that I had to sit on my garden wall to prevent myself from falling. I was able to get an emergency appointment with my GP later that morning and she told me that the last blood test that I had had in June indicated that I was close to having Type 2 Diabetes. At the time I did not take much notice as I had had radiotherapy earlier in the year for prostate cancer and had had a number of side effects to deal with. What I had noticed that I had been steadily putting on weight over the last couple of years and now weighed more than 15 ½ stone (100 kgs). A healthy weight for me would be about 13 stone (82kgs).*

*My GP arranged for me to see the diabetes nurse that afternoon to talk me through the symptoms of type 2 diabetes, and how to improve this with diet and exercise. She also showed me how to self-monitor my blood glucose level using the electronic testing instrument the GP practice provided. In addition I was prescribed 500mgs Metformin tablets which I started on the following day.*

*I am fortunate to have a dog and I go for a walk which lasts between 1 and 2 hours every morning, but diet is a vital factor both in weight and diabetes control. The diabetic nurse gave me a diet sheet (The Glycaemic Index (GI) of some common foods) which I have really taken to heart. I have cut out potatoes and starchy food as much as possible.*

*On 18<sup>th</sup> March I had a telephone consultation with my GP and she was delighted, and I suspect a little surprised by the low glucose readings and advised that I should discontinue the medication, keep an eye on my new diet and continue my dog-walking routine.*

*The diet I have stuck to is as follows:*

**Breakfast:** *Crunchy oats granola or muesli with a few slices of banana or other fresh fruit.*

**Lunch:** *2 slices of granary bread with cheese or fish (I have abandoned all other bread, cakes, pies, and pastries!*

**Dinner/Supper:** *Mixed vegetables, fish (poached in foil in the oven) or a small quiche or something like cauliflower cheese. For pudding I usually have plain yogurt and fresh fruit. When I feel the need for something sweet, I eat some fruit or have some dark plain chocolate with my coffee.*

*Being a scientist, I was curious about the impact of exercise on the metabolic process as reflected in my blood glucose levels. Normally I walk between 1 and 2 hours. As an experiment I omitted these walks between Sat 2 April and Thursday 9<sup>th</sup> April. After 3 days the glucose readings increased from 5.3 to 7.0. reducing again a couple of days after I started exercising again. Of course, one should repeat this test several times during the year to see whether these results are replicated.*

*My problem is that I like food and I am also a 'comfort eater', especially now that I am living on my own. When I get bored, I have the tendency to snack.*

*The problem I face now is not to find a new life-style but to maintain it! In any case, trying consciously to develop a better life-style so that I control my diabetes has meant that I have also lost weight, about 2 stone –and I feel better for it.*

*What is clear that is that it is possible to prevent pre- diabetes developing into Type 2 diabetes with diet and exercise **and** will-power!*

## **A history of diabetes, the development and use of treatments right up until today.**

- Approximately 1550. BCE. (**B**efore **C**urrent **E**ra)  
An Egyptian papyrus mentions a rare disease that causes a person to lose weight rapidly and urinate frequently. This is thought to be the first reference to diabetes.
- 250 BCE  
The creation of the term “diabetes” is credited to Apollonius, which refers to a disease which drains patients of more fluid than they can consume.
- 131-201 CE (Current Era)  
A Greek physician, Galen, theorises that diabetes is an affliction of the kidneys. After this period, diabetes is rarely mentioned.
- 1025  
A detailed account is published describing the sweet urine of people with diabetes abnormal appetite, diabetic gangrene and sexual dysfunction.
- Up to 11th Century  
Physicians start tasting the urine, and this is apparently how diabetes is given its second name mellitus, meaning ‘honey’ in Latin.
- 1770-1800  
The sweet taste in the urine of people with diabetes is thought to be due to excess sugar in the urine and the blood. Diabetes appears fatal for some, leading to death within five weeks, while others live much longer.  
This is the first indication of two different types of diabetes: type 1 and type 2.
- 1800s  
The term “glycogen” is coined after the discovery of a substance formed by the liver that is the same sugar found in the urine of those with diabetes.
- Early 19th Century  
During the Franco-Prussian War, a French Physician noticed that restricted diets helped his patients, and calorie intake is recognised as important.
- 1869  
Medical student Paul Langerhans reveals that the pancreas contains tiny cell islands:

they go on to be referred to as the “Islets of Langerhans”.

- Early 1900s  
The name “insulin”, is used, in reference to the substance secreted by the tiny islet cells in the pancreas. Insulin is Latin for “insula”, meaning island.
- 1919  
“Total Dietary Restriction in the Treatment of Diabetes”, reveals case records of diabetes patients treated with the ‘starvation diet’. The treatment helps extend the lives of diabetes patients, but many die as a result of starvation.
- 1920s  
Frederick Banting conducts vital experiments on dogs linking the pancreas and diabetes. With Charles Best they demonstrate that administering the islets of Langerhans can treat high sugar levels.  
James Collip purifies this insulin and it is treated for the first time on a human, 14-year-old Leonard Thompson. The work is considered a great success. The average life expectancy for a child with type 1 diabetes at the beginning of the 20th Century is roughly a year; Leonard lives until the age of 27, when he eventually dies of pneumonia. The research group are given the Nobel Prize in 1923. Eli Lilly strikes a deal for the first mass production of insulin in North America.
- 1936  
Research is published which divides diabetes into type 1 and type 2 based on the degree of insulin sensitivity in patients.
- 1940s  
Insulin treatments continue to develop and by 1945 the life expectancy of someone with diabetes is increasing. By 1945, a newly-diagnosed 10-year-old has a life expectancy of 45 years; a 50-year-old might live for another 16 years. The first hospital blood glucose monitoring system and the Clinistix “dip-and-read” urine test are developed which allows instant monitoring of blood glucose levels.
- 1955  
The first oral drug is developed, to help lower blood glucose levels.
- 1960s  
Urine strips are made available for home testing helping people with diabetes get faster readings. Blood testing technology also makes advances. Dextrostix are developed, testing strips which require a drop of blood for a minute. The blood is then washed off and an indication of blood sugar levels is revealed on a colour chart. Doctors at the University of Minnesota attempt the first pancreas transplantation in an attempt to cure type 1 diabetes.
- 1970s  
The first insulin pump is invented.  
  
1977. The HbA1c test is developed, indicating average blood sugar over the past 2-3 months, by measuring how much sugar is stuck to red blood cells.

This is a much more accurate indication of control compared to a one-off test.

- 1980s  
Humulin, the first biosynthetic human insulin, is approved for distribution in several countries. It is identical to the structure of human insulin and has the advantage of being less likely to lead to allergic reactions than animal insulin.
- The first insulin pen delivery system, called the NovoPen, is introduced in 1985.
- 1991  
The World Health Organisation launches World Diabetes Day in response to the rapid rise of diabetes around the world. It is held on November 14, the birthday of Frederick Banting.
- 1992  
Medtronic releases the MiniMed 506 insulin pump, which balances insulin requirements to food intake
- 1993  
The landmark Diabetes Control and Complications Trial (DCCT) report is published, demonstrating that regular activity and good nutrition help to improve diabetes control and stave off the risk of long-term health complications.  
Instant Glucose tablets are introduced, marking a significant development in treating hypoglycaemia.
- 1996  
Eli Lilly markets Humalog (lispro), a genetically engineered insulin which alters how insulin is absorbed.
- 1997  
Dr Richard Bernstein publishes 'Diabetes Solution' which addresses lowering carbohydrate intake as a means of achieving good blood glucose control and avoiding diabetes-related complications.
- 2000  
There is growing interest in islet cell transplantation as findings are published from seven patients with type 1 diabetes who undergo the procedure as a means of helping them achieve insulin independence.
- 2013  
The University of Cambridge trials an artificial pancreas which combines the technology of an insulin pump with a continuous glucose monitor.
- 2015  
The iLet, is developed, a bionic pancreas that delivers both insulin and glucagon every five minutes. The device is described as a "bridge to a cure" for Type 1, and is due to be launched this year

- The incidence of Type 2 diabetes is growing rapidly due to unhealthy high sugar diets, obesity and not enough exercise
- We are now seeing that remission from type 2 diabetes is possible using a very low carb programme to dramatically reduce weight and reduce reliance on medication.
- New technologies are being developed which enable people to gain greater control over their blood sugar levels, reducing the risk of complications.
- Looking to the future, breakthrough milestones we have to look forward to include the FreeStyle Libre being prescribed to everyone with type 1 diabetes who qualifies for the technology.
- The FreeStyle Libre, a system with a sensor attached to the arm which is used by Theresa May, provides continuous glucose monitoring and enables fewer finger prick tests. It was made available on the NHS a year ago.
- From the moment the FreeStyle Libre was made available in Europe in 2014 it has received acclaim for its positive impact on people with type 1 diabetes. A UK study in 2019 revealed the device reduced incidences of low blood glucose in roughly 80% of people with type 1 diabetes.
- **The system is currently being used by one million people with type 1 diabetes and half a million with type 2 diabetes across 44 countries.**
- But with more people being diagnosed with type 2 diabetes and the FreeStyle Libre offering freedom of needles for those with type 1 diabetes, demand is expected to increase.
- Since its launch there have been complaints of “postcode lottery” access to the device, with only 3-5% of people with type 1 diabetes in England having access despite 20-25% being eligible.
- People who are not eligible for the Libre currently have to self-fund their access to the technology.

### Cell Therapy

- Although still in the very early stages of development, cell therapy is one of the biggest hopes towards developing a cure for diabetes, **especially for type 1 diabetes**. Replacing the missing insulin-producing cells could potentially recover normal insulin production and cure patients.
- However, early attempts to transplant pancreatic cells have largely failed, mostly due to immune reactions that reject and destroy the implanted cells. The lack of donors is also a limitation.

**Please, if you have any of symptoms of diabetes, contact your GP. If in doubt, find out.**

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## ORGAN DONATION: HELEN'S STORY

During March 2008 my son Ben was suddenly taken into hospital needing a blood transfusion, he had always been fit and well so this was a considerable shock. Looking back, I can see that his high-pressure job of Training Manager for a large company; travelling all over the country to train new sales personnel, working long hours and eating many fast food meals was not conducive to his health; but naturally I was still extremely worried.

During my visit to see him at St James Hospital Leeds I could see Ben was extremely poorly, after various tests his diagnosis was 'severe kidney failure' and he would require permanent kidney dialysis. I remember sitting at his bedside as Sister Maria gave Ben the verdict; after a second or two of shocked silence I immediately said "well Ben can have one of my kidney's". Sister Maria pointed out that many tests would need to be completed to ensure that I would be a suitable donor. Looking back, I realised she was being tactful, apart from blood and other matches necessary, I was overweight so would need to lose about two stone!

Ben's health improved a little on dialysis and an initial meeting with his consultant, advised that donation should only take place after two years to make sure that the original cause for the kidney failure would not return. A month or two later I returned to Leeds for initial tests to ensure my blood group was compatible and given a weight target which was non negotiable. All seemed perfectly achievable to me at the time and I was thrilled. The remainder of my tests and examinations would take place in Oxford hospitals.

The following two years were extremely difficult for Ben, still living in Leeds. He had lost his job as it was totally incompatible with requiring dialysis several times a week. Feeling desperate he decided to undertake home dialysis, however, this is not quite as efficient as dialysis in hospital and he would frequently be re-admitted to hospital.

Each test result I undertook moved me nearer to donation. However, I found the last winter the hardest time to drop the last few pounds. Finally, we were informed that donation could go ahead on St George's day, 23<sup>rd</sup> April, 2010.

We were both admitted in the evening of the previous day as the Renal Unit at St James Hospital is so very busy. My husband would stay in a room at the 'cancer hotel' within the hospital where I would join him after discharge until strong enough to return home to Charlbury.

As Ben's Mother I never had any hesitation or doubt in offering a kidney, I think most mothers would feel the same, however, we are all different and the NHS ensures that no pressure is ever felt. I have a strong belief in Christ which possibly gave me strength.

In the morning as I showered, I felt none of the terror usually experienced prior to an operation, in fact I felt excited. On the way to theatre the Charge Nurse remarked to my husband "Whatever your wife is on, I want some". I mentioned I could feel the presence of God and was really happy. I have never felt anything so amazing before or since.

The operation went well, I was informed it was ground breaking with two surgeons undertaking keyhole surgery. I found out from a Muslim Doctor who had been in the

theatre that everyone of all faiths could feel the presence of God! Even those of no faith witnessed an extraordinary experience.

Ben recovered very well and it was so lovely to see him return to health. I returned home before him but soon we were both feeling good.

All 'Living Donor's' are awarded a badge in thanks for their donation, which was a complete surprise. I just felt so very pleased that I could help Ben by giving him a part of me. He did worry beforehand about my health but I reassured him that I would not withdraw my offer.

All 'Living Donors' as we are called are given an annual health check for the rest of our lives to ensure our continued health. In the NHS donor leaflets it states that living donors often live longer due to this!

There are some organs which we can manage without and how brilliant to be able to help anyone by offering one of yours. I am always astounded when such an offer is made to someone they do not know.

Helen  
July 2020

## Living Organ Donors

Across the UK, more than 1,000 people each year donate a kidney or part of their liver while they are still alive to a relative, friend or someone they do not know.

The most commonly donated organ by a living person is a kidney. A healthy person can lead a normal life with only one functioning kidney and therefore they are able to donate the other kidney to help someone in need of a kidney transplant.

Part of a liver can also be transplanted from a living donor to help someone in need of a liver transplant.

We are all familiar with blood donation. In addition, living donors can give platelets in their blood, removed bone from a hip replacement and blood stem cells made in the body's bone marrow.

New mothers can donate cord blood taken from the placenta and umbilical cord after the birth of a baby, blood which otherwise would be discarded. Some is suitable for clinical transplant whilst the remainder is available for research into new cell therapies. Many lives have been saved by stem cells from a donation of cord blood.

Much more information is available at:

<https://www.organdonation.nhs.uk/become-a-living-donor/>

or by calling: **0300 123 23 23**

The source of the information which follows is: <https://www.organdonation.nhs.uk>

## **Organ donation law in England changed on 20 May 2020**

At the time the Bill was passed and became law in March 2019 there were more than 6,000 people waiting for an organ transplant in the UK. People die each day while on the waiting list. The new law will help to reduce the number of people waiting for a life-saving transplant.

**What is organ and tissue donation?** Organ and tissue donation is the act of giving your organs and/or tissues to help save or improve the lives of others when you die. One organ donor can save or transform the lives of up to nine people. Tissue transplants can also significantly improve a person's quality of life. This might be a cornea to help someone see again, a replacement heart valve to treat a heart defect, or skin to treat severe burns.

### **What has changed?**

Organ donation in England has moved to an 'opt out' system. You may also hear it referred to as 'Max and Keira's Law' in honour of Max who received a heart transplant and a girl, Keira, who donated her heart.

This means that all adults in England will be considered to have agreed to be an organ donor when they die unless they have recorded a decision not to donate or are in one of the excluded groups.

### **Who will the changes affect?**

These changes will affect all adults in England unless they have recorded a decision not to donate or are in one of the following excluded groups:

- Those under the age of 18
- People who lack the mental capacity to understand the new arrangements and take the necessary action
- Visitors to England, and those not living here voluntarily
- People who have lived in England for less than 12 months before their death

Family will still be approached and faith, beliefs and culture will continue to be respected.

We still have a choice whether or not we wish to become a donor. Facts to help us decide about organ donation are at: <https://www.organdonation.nhs.uk>

### **Why has the law changed?**

The law has been changed to help save and improve more lives. Every day across the UK, someone dies waiting for a transplant.

## **What do I have to do?**

Everyone is asked to:

1. Record their organ donation decision on the NHS Organ Donor Register
2. Tell their family and friends what they have decided

<https://www.organdonation.nhs.uk/register-your-decision>

If you would like to speak to somebody about your choices, please call the dedicated phone line:

**0300 303 2094**

Mon – Fri: 8am - 8pm

Sat and Sun: 8am - 4pm

**The website has an easy to read fact sheet and answers the most frequently asked questions.**