





Talking Type 1...

# Not OK with needles?



## Living with a phobia (or fear) of needles

Needle phobia is a term that describes feeling extremely anxious about needles or injections.

The anxiety can lead to some people avoiding situations where they may come into contact with a needle (for example a vaccination or blood check) as often as possible.

When you have a needle phobia, and you to come into contact with a needle you may feel:



Scared



Tearful







Hostile or agitated

Dizzy or faint

A really strong urge to run away

A fear becomes a phobia when it's becoming problematic – for example if you're so scared of needles that it's starting to compromise your health because you feel too anxious to get a blood test. It's normal to dislike needles, and there aren't many people who feel completely relaxed during an injection or blood test.

People aren't regularly in a position where they have to deal with needles. However if you have insulin treated diabetes, needles are something that are part of your daily life. This resource is designed to help people who live with any kind of diabetes.

#### Talk to us about Talking Type 1!

We'd love to hear your views on this resource and whether it's had an impact in your life.

Simply scan the QR code with your smart phone, or go to https://www.surveymonkey.co.uk/r/QDFH7HP to complete an anonymous 5-minute survey that will help us to evaluate our work and develop new resources in the future.



#### These are the experiences of some people living with diabetes and a phobia (or fear) of needles:

"People at work laugh at me - they say how can you be scared of needles when you do so many injections all the time?"

"It's the run up to it - my mind goes crazy!"

"I build myself up for ages if I know I have to have a blood test. It's never as bad as I think it will be, but I can't help myself."

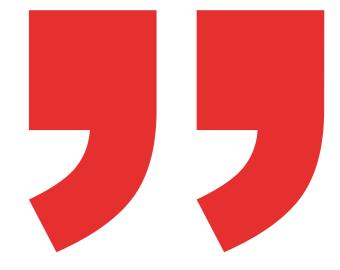
"I need to have people with me, like my parents or my boyfriend. I can't do it on my own."

"I know I need to move my pump around, but I can't get the idea out of my head that some areas of my body are way more painful than others." "I think for me it's about control...

If I'm not doing the injecting myself
I really hate it."

"I knew the symptoms I was getting were probably Type 1 diabetes, but because of my needle phobia getting diagnosed was my worst nightmare. I avoided going to the GP for ages... I got so ill."

"There have been times where I've completely freaked out in the phlebotomy clinic and it was really embarrassing. I feel like they see me coming as soon as I walk through the door now, and it makes me feel even worse!"



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## Is it possible to have a needle phobia when you live with diabetes?

Yes, definitely! - Things might look a little different to someone who has a needle phobia but doesn't depend on daily insulin doses.

#### Some people with insulin treated diabetes who experience needle phobia may:

- feel that they need someone else to inject their insulin for them
- be able to inject their own insulin but only with a lot of mental and emotional preparation first
- make particular 'rules' for themselves about needles (like only checking on particular fingers, or injecting into particular areas)

Some other people may be able to manage all of their diabetes injections/pump site changes and blood glucose monitoring with few issues, while still having a big fear of needles in other situations (like if someone else is injecting them).

This booklet is designed to help you think about your fear of needles and some ways that could help you to overcome it, so that your quality of life can improve.

Taking steps to overcome your fear might help with your diabetes management too. It might help to go through this booklet with a member of your healthcare team so that together you can identify what is causing your fear, and strategies that might help you to manage it.



#### Do I have a problem with needles?

#### Here is a list of symptoms that people may get when their relationship with needles is becoming a problem.

If you feel any of these things apply to you, you can use the boxes to tick off any thoughts, feelings or actions you may have recently experienced.

#### Have you felt this?

- Reluctant to do anything that could mean an additional injection/blood glucose check is necessary (like taking a correction dose for high readings)
- Extremely anxious in the run up to appointments in case I'm told I'll need an injection
- Really tense during injections
- Panicky and/or sick when I have to go for an injection
- Uneasy or panicky if there are needles present in the room or I see a picture/video of a needle
- Extremely sensitive to the discomfort of injections
- Really worried about injecting away from home or in public

#### Have you thought this?

- I can only check my blood glucose on particular fingers/parts of my fingers
- I can only inject my insulin/ have my pump cannula in particular locations
- I can only have injections/ blood taken if I've got a friend/family member there with me
- Injections aren't safe
- I can only have an injection/ blood taken at a particular place or with a particular professional
- I can't cope with having an injection/ blood taken

#### Have you done this?

- Taken a really long time to inject insulin or check my blood glucose because I felt anxious
- Kept my injections or pump to a particular area of my body, despite knowing I need to rotate my sites
- Avoided any injections that were additional to my usual Type 1 diabetes injections (for example the flu jab)
- Become upset, tearful or aggressive in the run up to, or during an injection
- Only checked my blood glucose on rare occasions (for example if I felt ill) because I wanted to avoid the finger prick
- Got other people to inject me because I felt too anxious to do it myself
- Deliberately 'forgotten' about an appointment that involved an injection
- Told a healthcare professional that I'd book a blood test for a later date/different location, when I had no intention of going



If you have ticked off a number of items on the list above, including some actions, your relationship with needles is probably a problem, and you might have a needle phobia.

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## Effects of needle phobia on diabetes management

If you're not regularly checking your blood glucose or you're skipping insulin injections you could be at risk of running your blood glucose levels higher than recommended, which over time will be causing problems for your body.

#### Signs that your body is regularly running higher blood glucose levels include:

- Feeling tired
- Feeling thirsty all the time
- Needing the toilet a lot (in particular during the night)
- Being irritable
- More prone to water infections like thrush or cystitis

Prolonged high blood glucose levels damage delicate blood vessels in your body – for example in your eyes, kidneys and also the nerve endings around your body. It can also increase your risk of cardiovascular disease which can increase the risk of heart attack or stroke at a younger age.

High blood glucose caused by not having enough insulin can lead to your body making ketones. These can make you feel unwell and if you live with Type 1 diabetes it can lead to a condition called diabetic ketoacidosis (DKA) which can be serious and require a stay in hospital, and definitely more needles.

If you're avoiding other aspects of your essential diabetes care such as getting your HbA1c or annual blood checks done, or going for your flu vaccination, you could be putting yourself at very significant risk of having an undiagnosed issue or developing a severe illness.

If you're not rotating your injection sites for your insulin pen or pump, you are at risk of developing scarred areas under your skin called 'liphotrophies' – these feel like lumps and can really interfere with the insulin you inject getting into your blood stream properly. Insulin can get 'stuck' in a lump, meaning it doesn't get in to your blood stream, and sometimes a lump can suddenly release the 'stuck' insulin, causing your blood glucose to drop suddenly putting you at risk of hypoglycaemia (a hypo).





Dr Steve is a diabetes consultant. We asked him about the extra blood checks that get done in diabetes services, and why people with diabetes are advised to get the flu jab.

#### Why do people with diabetes need to have extra blood checks at clinic?

Checking your blood is important when you're living with diabetes but unless there's a problem the extra checks we do shouldn't happen that often.

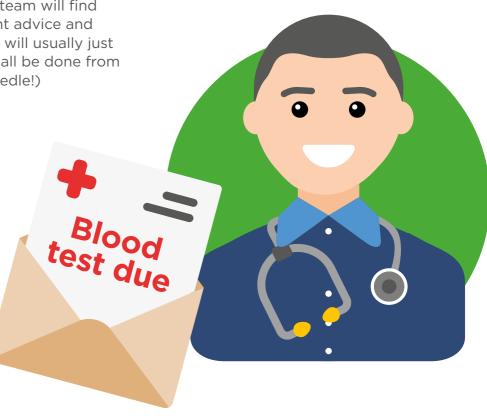
Certain blood checks are important for people living with diabetes as they tell you how things are going with the diabetes management generally (your HbA1c check), and also give vital information about other linked things like kidney function, cholesterol levels, thyroid function and tests for Coeliac disease which can often accompany diabetes.

Your HbA1c check is important and will be needed at most clinic appointments. Without it you won't know how your diabetes has been doing overall and the people in your healthcare team will find it hard to give you the right advice and support. The other checks will usually just be done annually and can all be done from one blood sample (one needle!)

#### Why is the flu jab so important for people with diabetes?

Influenza, more commonly known as flu, can be serious, and can cause complications such as pneumonia. Flu can be worse in people with diabetes as it can make diabetes much harder to manage and can lead to some people needing to be admitted into hospital for treatment.

All people with diabetes are usually invited for their flu jab once a year, usually during the autumn. The vaccine, which is given at the top of your arm, will be slightly different each year, which is why it's an annual injection. Having your flu jab is the safest way to avoid getting the flu and any serious complications associated with it.







#### Meet the phlebotomist

The people who usually do your blood checks at the hospital or the GP surgery are known as 'phlebotomists'.

Deborah has been working as a phlebotomist for 22 years and is the head phlebotomist at the hospital she works in. Here are some of her top tips for managing things when you feel anxious about needles.\*

- If you know you are going to go for a blood check, tell the person on the phone when you're booking your appointment that you feel anxious about needles. We can book you an appointment at the end of clinic so that you have all the time you need and aren't rushed
- What you do, and what we do during your blood check is completely up to you – you can ask us not to say anything about what we're doing, or you can ask us to tell you everything that's going on. You can look or not look, and we won't be offended if you need to do something distracting like listening to music or looking at your phone
- If you book your blood check in the community (e.g. at your GP surgery) it's likely that you'll get the same person doing your checks - this can help if one of your anxieties is not knowing what to expect during your blood check
- You can ask your phlebotomist about different types of needles (like butterfly needles) that might help blood checks to feel a bit easier
- You can sometimes get numbing creams and liquids prescribed by your GP, but you need to see the phlebotomy team before you put it on so that they can tell you exactly where to apply it
- Think about your clothing you need to wear a top with short sleeves or sleeves that can be easily rolled up

- Your body temperature and hydration level can affect how easy it is for us to do a blood check - you need to be warm (but not hot) and well hydrated. It's also easier for us to take blood if your blood glucose is not too high
- If you feel like you need some time to get used to the phlebotomy room before you go for a blood check you can ask us.
   We can usually organise a time for you to come in and have a look around
- If you want to know more about what we do and what happens to your blood once it's taken, you can ask us about that too.
   We're more than happy to tell people about what we do and we might even be able to organise you a tour of our labs!



\*you might find that not all of Deborah's tips will apply in the area that you live, but if you're finding that you're unhappy with the services you've been receiving, you could consider contacting your local NHS feedback service.

#### What causes needle phobia?

Sometimes people have a very clear reason for developing a needle phobia, but other times it's not so straightforward.

Below are some common situations that can lead to people developing needle phobia over time. You might find it useful to tick off any that you feel apply to you.

- You have a family member (often a parent) who has a severe needle phobia
- You had one or more medical procedures as a young child (not always to do with diabetes) that were scary or painful
- You had Type 1 diabetes as a child and there were a lot of arguments/stress before your insulin injections

 You had a needle phobia before you were diagnosed with diabetes

Can you think of any issues or events that you feel might have contributed to your needle phobia?

#### What keeps needle phobia going?

Once someone feels anxious about needles, there are two main ways that this anxiety can keep going and get worse; avoidance, and the way you behave around needles.

#### **Avoidance**

If you feel anxious about needles, you may have avoided particular situations, like injecting in a public place, going for blood tests, having a vaccination, or doing your own insulin injections. Avoiding needles works to reduce your anxiety in the short-term, but in the long-term you never get the chance to learn that you can cope with needles and that the things you fear aren't usually as bad as you expect them to be.

If you don't put yourself in a position where you can challenge your fear, you never get the chance to overcome it and it will keep going.

#### Behaviour

When you feel anxious, your body naturally tenses up and releases stress hormones into your blood stream because it's feeling threatened and wants to protect you.

However, the more tense and stressed you are when you are having an injection, the more sensitive to pain you are likely to be, and a small injection can feel really painful.

Some people become very emotional in the run-up to and during an injection or blood test. You might become snappy, grumpy or hostile, or you might become tearful. This can sometimes lead to difficult or embarrassing interactions with friends, family or healthcare staff, and the worry about doing or saying something mean or embarrassing the next time you have an injection can add an extra layer of fear to your feelings about needles.

Is there anything that you've been avoiding because of your needle phobia? You can use this space to write it down

#### What support is available for me?

- Talking to your diabetes team and explaining how you feel about needles is the first step - this is a really common issue and your team can support you with it. If you're regularly skipping checking your blood glucose levels or insulin injections because of your phobia, it's essential that you discuss this with your team
- Your team can review your current management plan, and will be able to help you access support and education that can help you feel confident with managing your injections if you need it
- There may be technology available to help you monitor and manage your blood glucose more easily and effectively with fewer finger pricks. There may also be devices available that reduce the number of insulin injections you need to make directly in to your skin
  - 3 9 mmol/L

    15
    12
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- A lot of people find it helps to talk to other people with diabetes, because they really understand what it's like. This is called 'peer support'. Your diabetes team should be able to let you know about any local peer support groups, or you can find information on diabetes websites and organisations at the back of this booklet
- There may be other options available too, like access to talking therapy, either through a diabetes psychologist or another service. Getting support like this can help you to identify and change any unhelpful thoughts, feelings and actions that are causing your fear and keeping it going



#### What can I do to help myself?

The key skills you need to learn to overcome a phobia are relaxation, and the ability to challenge yourself to 'feel the fear and do it anyway'. Everyone is different, and you might find when you try out these techniques that some work better for you than others.

#### Relaxation

If you know that you get tense before an injection (and nearly everyone does), you need to learn to relax your body. Taking slow deep breaths in to your belly can help to relax your body and stop the release of stress hormones. Some people find it helps to tense their muscles as hard as they can and then relax them a few times. It can also be helpful to listen to relaxing music or a guided relaxation track before and/or during the injection.

#### 2 Practising distraction

If you find that your mind runs away with itself worrying about how bad the injection will be, it can help to give it something else to do as a distraction. Below are some ideas that you can use to distract yourself during an injection.

#### My relaxation playlist

Try to think of five songs, albums or artists that really relax you when you listen to them. You can write them down here and make yourself a playlist that you can listen to in the run up to and/or during your next injection.

ı				
2				
3				
4				



Play I spy in the room - see how many things you can find for every colour of the rainbow



Focus on the other parts of your body (e.g. by focussing on what your clothes feel like or fiddling with your watch)



Think or talk about something positive (like holidays)



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Use something as a distraction (your phone, headphones, a book, a brain teaser)



Try thinking of a list of things (animals, football teams, Star Wars characters, food) that start with every letter of the alphabet

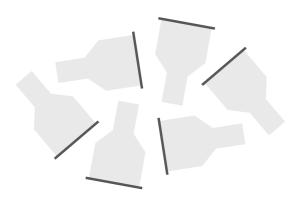
#### **3** Stay sharp

The needle tops for your insulin pens and the lancets for your blood glucose checks are designed to be single use and should be changed every time you use them. If you're not regularly changing you needles it's likely that that the ones you're using are blunt, which could be causing you unnecessary discomfort and putting you at risk of developing lumps that can stop your insulin working properly.

If you use an insulin pump it's really important that you do your pump set change on the correct day, as delaying it can increase the risk of your body not getting the insulin that it needs.



It's quite common for people with a needle phobia to feel faint or wobbly during an injection - this is often due to a reaction called vasovagal syncope, where your heart rate drops and the blood vessels in your legs widen, allowing the blood to rush to your legs and feet. The fear of fainting during an injection can then add in to the phobia thoughts. There is some evidence that lying down with your feet up during an injection can help to reduce the effects of vasovagal syncope, and some people find it helps to cross their legs and clench hard (like you're desperate for the toilet) to reduce the amount of blood that rushes to the feet.



### 4 Get your technique checked

Over time people can unknowingly start to develop bad habits around their injecting technique, and you might be making your injections more difficult than they need to be.

If you're finding checking your blood glucose or injecting your insulin hard, it might help to make an appointment with your diabetes nurse, who can check out your technique and advise you on any changes you could make.



#### **6** Fear ladder

A proven way to overcome phobias is to break them down in to little steps that you overcome one at a time. Try to think of ten situations involving needles and give each one a mark out of ten for how anxious each one makes you feel. Start at the situation with the lowest mark and do it over and over again until you are completely bored.

When you've done this you can give yourself a reward and move up to the next level. While the things at the top of your fear ladder may feel completely unreachable right now, when you've worked your way up all the other steps it will feel really achievable and you'll be amazed at how far you've come!

#### **Example of a fear ladder:**

#### First steps are the hardest!

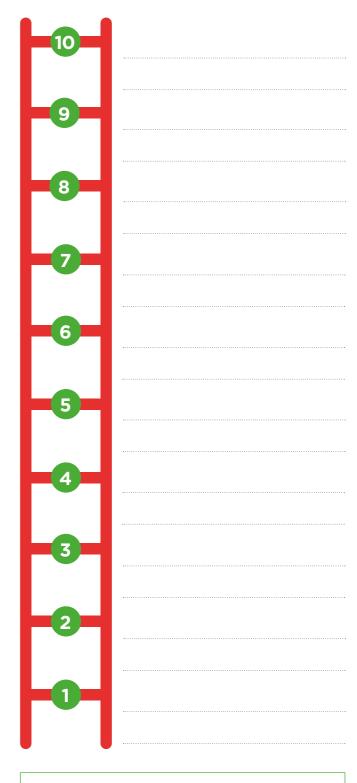
- 1 Looking at a picture of a needle in a book
- 2 Looking at a needle on the table in front of me
- Watch a video of someone getting a successful injection online
- 4 Watch someone else getting an injection
- 5 Hold a needle in my hand

#### Half way there!

- 6 Inject something like a stress ball or an orange
- 7 Sit in the phlebotomy chair at the GP surgery
- 8 Let the phlebotomist or nurse hold the needle next to my skin
- 9 Have an injection
- Have a blood test and celebrate my massive achievement!

You did it!!! Amazing work!

## Have a think about your own fears and write them on to this fear ladder:



When I achieve a step, I will reward myself with:

#### **Relapse prevention**

The road to overcoming issues like a phobia is never smooth, and you may go through times where things become more difficult, particularly if some of your old triggers occur.

It's important to remember that while it might take some time for your thoughts and feelings about needles to change and stabilise, what's important here is what you do. If you can stay committed to managing your diabetes as well as you can even when your mind is having scary thoughts, you are well on your way to overcoming this.

#### **Further help**

Always remember to use your own judgement when engaging with other people living with diabetes online. Everyone's diabetes is individual and in the interest of your own safety talk with your healthcare professionals before making changes to your own diabetes management.

#### **Organisations & websites**

Beyond Type 1 - A global charity based in America for people living with Type 1 diabetes. Also active on most social media platforms.

#### www.beyondtype1.org

Beyond type 2 - A global charity based in America for people living with Type 2 diabetes. Also active on most social media platforms.

#### www.beyondtype2.org

Bertie Online - An educational website with lots of useful information to help you understand and manage your diabetes in a way that suits you and your lifestyle.

www.bertieonline.org.uk

Diabetes UK - UK charity for people living with diabetes.

#### www.diabetes.org.uk

Digibete - A website full of resources and videos for children and young people living with Type 1 diabetes, and their families.

#### www.digibete.org

Type 1 Resources – A collection of resources for people with Type 1 diabetes that are reviewed by healthcare professionals and regularly updated.

www.t1resources.uk

#### **Hashtags**

There is a very active diabetes online community on twitter, try searching using the hashtags **#gbdoc #doc** or **#T1D** to get started.

#### **Books**

Nash, J. (2013). Diabetes and wellbeing: managing the psychological and emotional challenges of diabetes types 1 and 2. John Wiley & Sons.

This booklet was written by Clinical Psychologist Dr Rose Stewart in collaboration with people living with diabetes and NHS diabetes healthcare professionals. With special thanks to Adrianne Formstone-Roberts.

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