

Diagnosing and Living with Thrombosis

A patients perspective



About Me

My name is Clare Reynolds, I am 39 years and I am the Project Development Officer for Thrombosis UK. I am a mum of two and live in Liverpool with my partner. I am also a chronic thrombosis patient, I have antiphospholipid syndrome and have had more blood clots than I can currently recall. The most recent was five weeks ago when I had multiple PE's in the left half of my lung despite anticoagulation of Fragmin 7500iu three times a day. Over the years I have had DVT's in the leg's, arms, groin, lung and brain. I hope my experiences as a patient but also from my work in Thrombosis UK can give you all an insight into the patient journey and what it is like to live with Thrombosis.

Firstly if I can ask you all to look at the picture on the right hand side of this slide.

This was taken three days before I presented with TIA's at the Royal Liverpool Hospital last October. Apart from a slight facial droop on the day I did not look much different. I would like you all to remember this as this is the face of Thrombosis – which I think you will all agree looks pretty much the same as the average person walking past you on the street.



Diagnosis

The issues currently affecting patients can be no more accurately described than me recounting a phonecall I had for the charity just hours before me typing this presentation.

The tale of patient A

Patient A was 6 weeks post DVT diagnosis and because she couldn't get a doctors appointment for 3 weeks she called us to ask if her leg swelling and discolouration was normal.

During the course of the conversation it was established that like many other patients the following issues had arisen:

- Clear lack of explanation as to what has happened and what to expect.
- Incorrect information given at diagnosis.
- Although follow up was given at an anticoagulation service the patient felt alone and uninformed.
- Patient felt that she had learned more in a 10 minute conversation with myself than she had done in the whole process.

Diagnosis - Cont

Whilst my previous slide may sound like a very negative take on the patient experience it is not an uncommon occurrence - As a charity we are currently receiving increasing numbers of calls similar to this one on a weekly basis. At Thrombosis UK we are not medically trained so quite often we cannot help these people all we can do is redirect them back to a GP or A and E.

My aim today is not to slam the NHS or its services but to ask you as front line people who have an interest in Thrombosis to think of ways you may be able to improve things in your trusts, clinics and surgery's to stop this from happening. Our Let's Talk Clot's Events go some way to promoting awareness and this doesn't and shouldn't stop after the one event or the three week period we are currently running it for. The NHS has grown very good in prevention and diagnosing but work still needs to be done to help us prepare and give patients the ability to be able to live and deal both mentally and physically with what a Thrombosis diagnosis can bring.

Create a patient charter

Give newly diagnosed patients Thrombosis UK as a resource

Try mystery shopping the DVT diagnosis pathway

Speak to your patients

Living With Thrombosis

This subject is something I could do a whole one week conference on. But for today I am going to concentrate on two main areas:

- Psychology of Thrombosis Patients.
- Living with Thrombosis as a chronic condition and its impact on life.

Quick question: How many of you in here deal with long term Thrombosis patients or as I am one myself repeat offenders? So not necessarily on the initial diagnosis side more the management of the condition.

How many patients in general post diagnosis, have you felt are either highly anxious, panicky, worried over every little itch?

Am I going to die?

I don't have anyone
who understands

No one is listening to
me

I feel so alone!

Psychology

What's going on inside the patients head?

Quite often as explained in diagnosis there are a number of issues that lead to patients with Thrombosis becoming anxious.

Imagine you have just been diagnosed with an illness you know very little if anything at all about, you go home with little or no information, whilst you are receiving the diagnosis you aren't thinking about what you need to ask, so you go home with unanswered questions. You then realise that there's no one to ask until a follow up appointment is arranged which in some cases can be weeks! Within a week, the symptoms you first experienced either aren't getting any better or in some cases are worse – as you are not sure what to expect you think it is happening all over again. In some cases there have been one or several episodes of misdiagnosis so you begin to wonder if it is another will it be picked up or will you die?

If we look at the above scenario you can start to see where anxiety starts to build – A lot of the time when these patients call up they have worked themselves up so much they are in a high state of anxiety and the first 10 - 15 minutes of a conversation can be spent just literally calming them down.

Psychology - Cont

This pattern can plague patients for months and years if not managed correctly. With the growing dependence on the internet and social media patients believe they are more informed than ever. From experience they tend to trust Google more than medically trained staff or new found friends they have found on Facebook with their condition. Sadly if not used correctly these tools just do not help and increase the anxiety even more. The doctors waiting room is no longer confined to bricks and mortar!

How do you tackle this? For me it has to start as soon diagnosis is confirmed. There is no re inventing the wheel here, all I'm asking is that you remember the scenario I described and place yourself in that position. Talk to your patients and gain knowledge of their experience and tailor your approach accordingly. It may not resolve it but it will go a long way to helping

How serious is a pulmonary embolism?

Pulmonary embolism is the sudden blockage of a major blood vessel (artery) in the lung, usually by a blood clot.. In most cases, the clots are small and are not deadly, but they can damage the lung. But if the clot is large and stops blood flow to the lung, it can be deadly.

Pulmonary embolism

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A pulmonary embolism is a blocked blood vessel in your lungs. It can be life-threatening if not treated quickly.

Deep vein thrombosis (DVT) is a blood clot that develops within a deep vein in the body, usually in the leg.

[Blood clots](#) that develop in a vein are also known as venous thrombosis.

DVT usually occurs in a deep leg vein, a larger vein that runs through the muscles of the calf and the thigh.

It can cause pain and swelling in the leg and may lead to complications such as [pulmonary embolism](#). This is a serious condition that occurs when a piece of blood clot breaks off into the bloodstream and blocks one of the blood vessels in the lungs (see below).

CancerClot

[BLOOD CLOTS & CANCER](#) [LIVING WITH BLOOD CLOTS](#) [RISK & DIAGNOSIS](#) [MY TREATMENT](#) [TOOLS FOR YOU](#) [VIDEOS](#) [GLOSSARY](#)



What are the risks?

Not everyone diagnosed with a blood clot can find an associated cause. However certain factors are known to increase the risk of clots. Here you can learn about what has been known to cause clots and find out if you are at risk.

Living With Thrombosis as a Chronic Condition

The last part of my talk today is an issue that is very close to home. There is no point me standing here telling you all how to live with it, so I would just like you all to know the impact it has and why if I ever pop up in a clinic or an A and E department of yours why I am like I am.

Thrombosis, impacts every single part of my life, from my job, to my children right down to when I go to bed and when I wake up. Now I am standing before you, and admittedly I am the extreme end of the Thrombosis patient scale – I clot through anticoagulants, I also bleed because of the level of anticoagulation I am on.

I am extremely fortunate as a patient that the team of doctors and nurses I have supporting me are fantastic – none more so than my consultant Vanessa Martlew. My journey hasn't always been smooth or problem free but my experiences have made me who I am today and the patient I am today.

Admittedly I am not now or never have been the easiest patient to deal with! It is in my nature to want to know and question every little thing especially about my condition. This not only mentally ensures I can deal with the diagnosis I have been dealt but also so that issues that have arisen in the past don't tend to raise their ugly head again.

Living With Thrombosis as a Chronic Condition - Cont

So what issues affect me?

- I do not look like I am ill even when I am ill!
- The impact repeat diagnosis' have had on my family.
- The impact of my condition on daily living, travel, work!
- The impact of my condition on other investigations and diagnosis'

All in Thrombosis is a part of me but hopefully it doesn't control me and I hope that my experience can be used to help others in my position lead a better life.

Finally.....

How can Thrombosis UK help your help patients:

We are looking for medics to help us arrange patient days where patients like yours can access talks and information and meet others in a safe environment. We need a local medical lead for each one though where your help comes in. Our supporters our crying out for them. In terms of support these are invaluable especially with the time pressures there are currently within the NHS.

If any of you want to discuss this further please contact me on Clare@thrombosisuk.org.

If time is not on your side and you feel patients need more time, information or just someone to talk to please direct them to us, we have a brand new website www.thrombosisuk.org with tonnes of downloadable resources and ways to access help. We also have a non medical advice helpline 0300 772 9603.

I hope this helps.

Any questions