

Your rights to Care

- A brief guide to what you need to know -

This leaflet gives a brief guide of some of your rights when it comes to looking after your health and accessing treatment, as well as examples of problems that people have faced. We will not cover all the issues here but will answer some of the more commonly asked questions.

For more information and support please contact OCD Action's professional advocacy service on **0845 3606234** (available 9am-5pm, Monday – Friday)

You have the right to make choices about your care and treatment provided under the NHS but it is not always easy to know what you are entitled to. Some important factors to remember are.....

- **You have the right to be treated by the NHS. If you have been diagnosed with OCD, the approved treatment is medication (usually an SSRI) and or cognitive behavioural therapy (CBT).**
- **Since 1st April 2009 patients have the right to choose where they have treatment when they are referred for their first outpatient appointment with a service led by consultants. Patients are also entitled to information to support that choice. The range of choice will develop over the next few years.**
- **In England you have the right to be offered at least four hospitals when you need to see a specialist, you can book the appointment yourself though your GP must give you the information first (an appointment slip, reference number, password, contact details).**
- **This means you can choose a hospital that has a shorter waiting list, or a hospital in a location more convenient for you.**
- **You cannot receive specialist treatment on the NHS (unless it is in an emergency) unless your GP refers you.**
- **You have a right to complain about any aspect of your health care and treatment you are not satisfied with.**

So what does this mean in real life?

The case studies below are typical examples of the problems that people face, and in each case we have set out the relevant rights and issues to consider.

Case example

Sunita

Sunita has lived with OCD for many years. She feels able to manage most of the time but when she experiences particular stresses her OCD gets worse and she is unable to leave the house because she fears the outside world is contaminated.

Sunita recognises that at these times she is quite unwell and is usually helped by a change or review in her medication. Sunita has an extremely good relationship with her GP whom she's known for many years. The GP understands Sunita's situation and has made home visits when Sunita is unwell as this has helped her recover quicker.

During a recent episode where Sunita became unwell again she contacted her GP practice explaining the circumstances and asked for a home visit because of her extreme fear of contamination should she go out. Sunita's GP had no free appointments and the only option the practice could offer was an appointment in the surgery with a locum GP. Sunita wanted to know what she could do

You are entitled to treatment from a GP where you are registered but you do not have an automatic right to see your own GP.

You cannot insist that a GP visits you at home, a GP will only visit you at home if they think your medical condition requires it. A GP can also decide how urgently a visit is needed.

The GP practice in this situation would not be breaching any contract they have with the NHS i.e. they are within their rights to provide care in this manner but Sunita could put a case forward that a home visit would be more beneficial for her health especially as it has been shown to be the case in the past.

Sunita could also claim that as she is unable to leave the house due to her worsening OCD, if she is left untreated she could become seriously ill. If you were to become seriously ill after a GP had refused a home visit, the GP could be found to be in breach of their contract with the NHS or could be found to be negligent.

Philip

Philip has recently become a volunteer at a day centre run by a mental health charity. He has OCD and BDD and was discharged from hospital 6 months ago having been detained under the Mental Health Act (1983) for 18 months. He was detained because of his intrusive thoughts and ideas of harming himself, which at the time were very serious.

Philip has made a good recovery and his new job as a volunteer has given a great boost to his confidence. He wants to move his life forward and work towards a career. The day centre asked him for 2 references, Philip gave one reference as a friend of his and the other as his psychiatrist to show how far he has come with regard to his mental health.

Philip would like to know what his psychiatrist has written as he knows that his psychiatrist keeps a record of all conversations – some of which Philip might disagree with or not recall. He wants to know what rights he has in this situation given he asked for his psychiatrist to provide this information.

Philip is allowed to see any medical report written about him that's been sent to an employer, prospective employer or insurance company, this report can only be written by someone that has been involved in his medical care.

The information provided to a third party, in this case the day centre, can only be what would be shared with Philip which means that if Philip has not been given that information by his psychiatrist it cannot be disclosed to anyone else.

Should Philip wish to access all his medical records, he has a right to request this and it is usual to be asked to put this request in writing. There can be a charge for this but it is only to cover the cost of copying the information (a maximum of £10 for computer records, £50 for manual records).

If Philip disagrees with what is written about him he has a right to request this is changed and must do so initially with the relevant healthcare professional (in this case his psychiatrist). If this does not resolve the situation, he has a right to complain via the NHS complaints procedure. As a final resort, he could complain to the Information Commissioner who may then make a decision to rectify, block, erase or destroy the information. This decision would only be made after the previous 2 avenues have been gone through as Philip's psychiatrist may have evidence to substantiate what is written.

Philip's psychiatrist may deem that certain information would cause serious harm to his physical or mental health and therefore deny this access, this has to be justified and a rationale provided.

Josh

Josh has recently been diagnosed with OCD by his GP, he was prescribed an anti depressant and 6 weeks of CBT which have now come to an end (although Josh is still on medication). Josh is feeling a slight improvement in his mental health though feels he's not yet recovered to a point of feeling well. What else can Josh do in this situation given he feels he's had all the treatment his GP was willing or able to offer him?

The National Institute for Health and Clinical Excellence (NICE) has produced guidelines for NHS staff when working with and treating people with OCD, the following is a brief summary of what they suggest is good practice.

If you have OCD and your symptoms are:

Mild - you should be offered

- Up to 10hours of CBT (either individual, group or telephone).
- If this does not help or suit you, you should be offered a choice of an SSRI or a further 10hours of CBT.

Severe - you should be offered either:

- An SSRI
- More than 10hours of CBT

Very severe – you should be offered:

- A combined treatment of CBT and an SSRI.

NICE recommend the same treatment as above if you have BDD be it mild, severe or very severe.

In general, healthcare professionals are expected to follow NICE guidelines but there are times when they do not. This happens when a healthcare professional judges that following the guidelines would be detrimental to a patient's specific medical condition, their general health or it would be contrary to the patient's wishes.

If you feel you are not getting the treatment that NICE recommend or that you are not benefitting from it, you should speak to the relevant healthcare professional about this e.g. GP, community nurse or therapist.

NICE also recommend that if you have been prescribed an SSRI and it has helped that you should continue to take this for 12 months. Please note that these are guidelines and as such not prescriptive but rather what NICE's research has shown is effective for those with either OCD or BDD.

For further information:

You can download the above guidelines at www.nice.org.uk/CG031

ICAS (Independent Complaints Advocacy Service) www.carersfederation.co.uk

NHS Direct (0845 4647; www.nhsdirect.nhs.uk)

You can also access your local:

CAB (Citizens Advice Bureau) or PALS office (Patient Advice Liaison service)