



Self-Advocacy Toolkit

Information and worksheets to help you to navigate the treatment system and to communicate more effectively.

Contents

Acknowledgements

Introduction

Accessing Treatment Flowchart

Advocacy Planning

Worksheet 1

Communication Skills

Preparing for Meetings

Describing Your Symptoms

What Treatment?

Worksheet 2 – Preparing for a Meeting/Appointment

Worksheet 3 – Meeting/Appointment Summary

Worksheet 4 – Medication Summary

Worksheet 5 – CBT Summary

Letter Writing

Making a Telephone Call

Worksheet 6 – Telephone Log

Improving Access to Psychological Therapies (IAPT)

Community Mental Health Teams (CMHT)

Making a Complaint

Worksheet 7 – Complaint Letter Writing Worksheet

Feedback

Please Read Before Using the Toolkit

This Self-Advocacy Toolkit is being produced as part of the Big Lottery Fund funded Advocacy Service at OCD Action. OCD Action's aim is to produce a set of tools that you can use and that reflect your self-advocacy needs.

Just ring us up: 020 7253 5272 or email us: advocacy@ocdaction.org.uk to let us know what you think, or go on social media to let us know how you used it. We have also included a feedback form at the back of the toolkit - please fill this out and post it back to us at:

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Acknowledgements

OCD Action is the largest national charity focusing on Obsessive Compulsive Disorder (OCD). We provide support and information to anybody affected by OCD, work to raise awareness of the disorder among the public and front-line healthcare workers, and strive to secure a better deal for people with OCD. Our services include a Helpline and an Advocacy Service and support to a UK-wide network of independent support groups for people affected by OCD. Information about OCD, our services, support groups and information resources on accessing treatment can be found on our website: www.ocdaction.org.uk.



OCD Action's Self-Advocacy Toolkit is a work in progress based on our experience as providers of issue-based advocacy to adults affected by OCD/BDD and related disorders over the last seven years. OCD Action is grateful for the helpful input from all those who attended the workshop on this at our Stakeholder Event in Liverpool in 2017 and look forward to amending and adding to the toolkit in the future from the feedback of all you who make use of it.

Finally we would like to acknowledge our use of the following documents which prevented us from having to reinvent the wheel:

Advocacy Toolkit – Disability Rights Wisconsin

Self-Advocacy Kit – Advocacy for Inclusion

Being Heard: A Self-Advocacy Guide for Carers – Carers Scotland

Patient Self-Advocacy Toolkit – Pulmonary Hypertension Association

Introduction

Self-Advocacy is speaking up for yourself to get what you need; it is something we might do every day for ourselves in small ways but we may struggle to do it effectively when we're trying to get the right care and treatment for our OCD or to ask for reasonable adjustments at work or college.

The aim of this toolkit is to help you to develop the skills and approach necessary to become an effective self-advocate. It aims to help you to identify what information and support you might need and where to get that. The majority of this toolkit focuses on informal routes to getting your voice heard and achieving your goals because that is usually the most effective way to resolve issues – directly with the person who can do something about it.

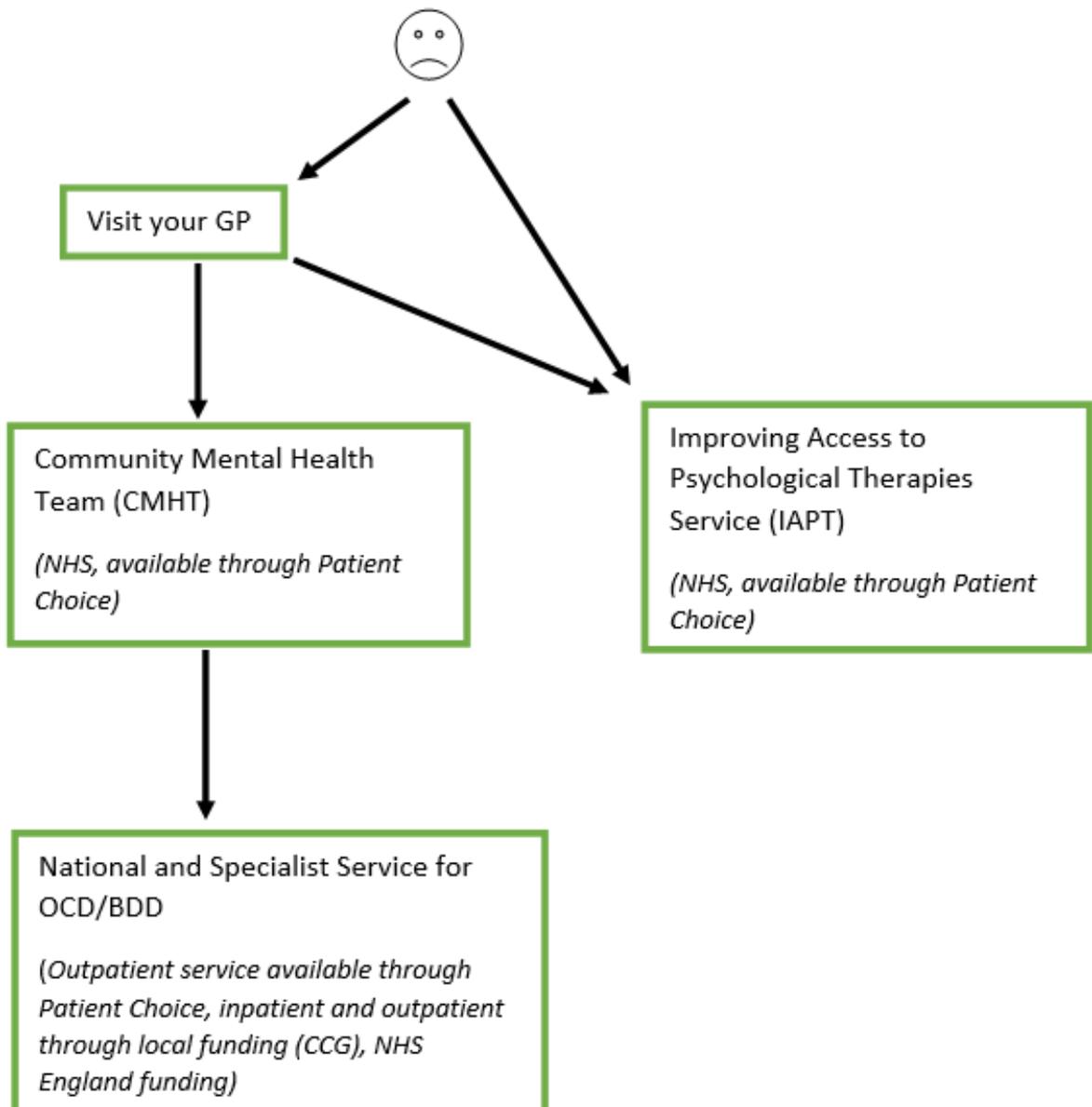
However, we have included a section providing information about the more formal complaint route to be followed where you have exhausted all other routes or feel that the more formal route is the right one for you and your concerns.

Most sections in this toolkit can be used for any number of situations but we're focusing on how to use them to access treatment for OCD/BDD and related disorders.

For those of you that have accessed treatment in the past and are seeking treatment again, we have highlighted some extra information for you in purple, so keep an eye out!

Accessing Treatment Flowchart

This diagram is designed to help you clearly identify which routes you can take to access treatment for your OCD/BDD or related disorder. It should help you with your advocacy planning. Details about some of these services can be found in this toolkit, and more detailed information is available on OCD Action's website: www.ocdaction.org.uk



Advocacy Planning

The first step in self-advocacy is to identify what you need and want and the steps you will need to take in order to achieve that; in other words, to develop an Advocacy Plan.

It is worth spending some time on this planning stage as it forms the foundation for any self-advocacy.

This version of the toolkit focuses on accessing treatment so we will look at the steps involved in planning how to get the treatment you need. So, the first question to ask is: **what is the problem or issue?** And here we're looking at a situation where the problem/issue is: **I need to take action against my OCD.**

The next question might be: **what is my goal?** And here we'll look at: **I want to access treatment for my OCD.**

So, what information might you need to achieve that goal? Where might you find that information? Who can you ask that might have that information?

Following our example, you might want to:

- Look at information on the OCD Action website: www.ocdaction.org.uk to see what treatment is recommended for OCD or phone the OCD Action Helpline to ask: 0845 390 6232.
- Read the NICE guideline on OCD treatment to see where you might be on the stepped-care model for treatment and what is suggested in terms of best practice, both for medication and CBT.
- Find out about self-referring to an Improving Access to Psychological Therapies (IAPT) service if you're in England – you can find the contact details of your nearest IAPT on the NHS Choices website: www.nhs.uk and find more information about IAPT in this toolkit.
- Identify the key decision-maker in your situation – who is the person/organisation who can give you what you want i.e. prescribe medication, refer you to the CMHT etc?

If you have had treatment in the past:

- Find the dates and details of any CBT or medication you've had in the past for your OCD and take that to your GP. (Or that information might be in your medical notes and you could make a note to yourself to remember to ask the GP for the details when you see him/her).
- Exercise your right to choose a Consultant-led outpatient service anywhere in England (including IAPT, CMHT and even the Centre for Anxiety Disorders & Trauma (CADAT)) so you could look on the OCD Action or the NHS England website for more information about how it should work. In addition, it would be good to have some idea of the service you want to be referred to – you could call OCD Action's Helpline to discuss your possible options.

The next step is to decide on your strategy; what **action** are you going to take to resolve the issue, which in our example is: **to get the treatment you need**. It's useful at this point to think about the **Self-Advocacy Skills** you are going to need.

We have put together some useful resources in this toolkit to help you with:

Preparing for/Attending Meetings

Letter Writing

Making Phone Calls

Communication

Top Tips

- Make a note of the date, time, name role and contact details of everyone you speak to; ask for decisions to be put in writing and if your request for treatment is being refused ask for a written explanation as to the reasons for this – although your health provider does not have to comply with NICE guidance if it is a quality standard (as it is in the case of OCD & BDD) they should provide reasons for not following it.

- Be prepared!

- Try to put as much as you can in writing – create a paper trail! Use the Letter Writing Tips, Making a Telephone Call, and Appointment/Meeting Worksheets to help you put treatment requests in writing and to keep a record of decisions made/actions promised in meetings and phone calls. Ask for all treatment decisions to be put in writing to you and keep all documentation.

- Be persistent! If you're not happy with the response you get from the person you speak to – ask to speak to their Line Manager to resolve your issue with them. The NHS is a hierarchical structure – make use of it!

- Or, if your GP feels they can't help – see someone else! If it's a group practice, you can see any GP and there may be one with a particular interest in and knowledge of mental health conditions.

- Get some support – don't be afraid to ask for help and information from others.

- Be organised!

And don't forget – you are the expert on you and your condition.

Self-Advocacy: Worksheet 1 – Making a Plan

Being clear about what you want to achieve is an essential first step in self-advocacy and this worksheet can help you to think clearly and make a plan.

What is the issue? What would you like to change?

.....

.....

.....

.....

What is your goal? What result would you like to achieve?

.....

.....

.....

.....

What information do you need in order to achieve your goal? Where can you get that information?

.....

.....

.....

.....

What support might you need to achieve your goal? Where can you get that support?

.....
.....
.....
.....

Who are the decision-makers that you need to influence to achieve your goal? What actions can you take? Who do you need to speak to?

.....
.....
.....
.....

I will call/meet with/write to by the following date:

If the person does not resolve the situation by the following date then I will call/meet with/write to

.....

Documentation that I will need:

.....
.....

What is the backup plan if this strategy doesn't work?

.....
.....
.....

Self-Advocacy Worksheet 1, part 2 – Making a Plan

Remember, you could have a different plan for each goal.

What is my goal?:

| ACTION What needs to be done? What steps am I going to try? | DATES Important dates: appointments, meetings, deadline | WHO Who do I need to speak to/meet with? Who's getting back to me? | PROGRESS What have I done so far? |
|---|---|--|---|
| | | | |
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| | | | |
| | | | |
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Communication Skills

Effective communication is an essential self-advocacy skill which ensures that you can get your point across in such a way that you are heard but also that you can hear and respond to what's being said.

What can get in the way of effective communication?

These are examples of barriers that can prevent us from getting our message across effectively and can stop us listening to the person we're speaking to:

- Our own state of mind – feeling too stressed, angry or upset to articulate our needs
- If we voice our concerns as a personal attack on the person we're speaking to this can lead to them turning off and not listening to what we're saying
- Speaking too quietly or shouting
- Not having the time or taking the time necessary to write the letter/email or make the call
- Environment (noisy or full of distractions) – find a quiet place to make/take a call
- Own experiences and opinions – guessing, presumptions, selective listening
- Feeling unprepared for a meeting or phone call

How can we avoid this?

- Take time to switch off and reschedule phone calls/meetings if necessary
- Set aside enough time and explain if time is limited
- Try to find a quiet space and avoid interruptions
- Be aware of your own thoughts and opinions and avoid making presumptions about what the other person is going to say
- Be clear about what has gone wrong in the past if that is something you want to get across but spend more time focusing on what needs to be different in the future
- Be well prepared for meetings and calls – use the tips and worksheets in this toolkit to help you

Top Tips

- Be assertive not aggressive
- Be respectful
- Try to stay calm!
- Is there room for compromise?

Preparing for Meetings/Appointments

You might be going to your GP to discuss your OCD for the first time or to ask for a referral to another service or you might be meeting with your psychiatrist to request a referral for more intensive and specialist treatment. Whatever the meeting, it's essential that you're prepared; that you have an overall plan - the following questions and tips can ensure that you get the best from any meeting or appointment you might attend.

Planning

- 1) Devise a strategy: What outcome do you want? Use the Advocacy Planning tool pages and worksheets.
- 2) What information do you want to get across? What questions do you want to ask and have answered?
- 3) Who is going to be present in the meeting? What are their roles? Why are they there?
- 4) Where is the meeting taking place? Is that somewhere you can get to?

Top Tips for attending a meeting

- Consider taking someone with you both for moral support but also to help you to self-advocate - they can act as a prompt if you forget to ask something, they can be helpful for remembering who said what in the meeting and they can make notes during the meeting of the main points discussed and any actions agreed
- Have the points that you want to raise written down in front of you so that you can see them in the meeting
- Try to find out who is going to be at the meeting - names and role descriptions. If you have concerns about anyone being at the meeting - don't be afraid to ask the reasons for them being there or request that they leave

- Be punctual – make sure you know where you’re going and how to get there
 - Don’t forget to take any documents with you that might be relevant – for example you might take **OCD Action’s GP Card** to an initial meeting with your GP or **OCD Action’s CBT Checklist** to a meeting with your therapist if you have concerns about the quality of treatment you’re receiving
- When the meeting starts, if there are no formal introductions, ask for people to introduce themselves so that you know who everyone is. Are there people at the meeting that you weren’t told about? Don’t be afraid to ask for them to leave if they are not directly relevant to your care & treatment
- Don’t be put off by authority figures. Be polite but don’t be talked over – if this happens, wait until the person stops speaking and then make your point
 - Monitor how you’re feeling – do you need to ask for a break?
 - Don’t be afraid to make notes in the meeting about what is being said/agreed – particularly the responses to the specific questions that you wanted to raise and who responded
 - If you don’t understand or aren’t clear what is being proposed by the people present ask for clarification e.g. if you’re going to be referred for treatment: clarify who’s going to refer you, how soon are they going to make the referral, what’s the treatment, (is the referral dependent on securing funding, how does that work), who’s going to treat you – what’s their expertise in treating OCD/BDD and related disorders, what are the waiting times like, what support will you get in the meantime, who will keep you updated with developments?
 - Don’t forget – you don’t have to agree to anything there and then – if you want time to think about things or talk through treatment suggestions with family and friends ask for that time and agree a timeframe for telling the meeting attendees of your decision. Just be sure that this isn’t your OCD stalling!
 - If there hasn’t been enough time for you to say everything you wanted to say and you have felt rushed then you could ask for a follow-up meeting or send a letter with your additional concerns/points and request a written response
 - As the meeting is coming to an end try to summarise to those present your understanding of what has been agreed or ask them to do so
 - Don’t forget to ask for timeframes for any actions agreed at the meeting/appointment
 - Depending on the type of meeting/appointment you might want to ask for minutes from any meeting to be emailed/posted out to you or you could email your own summary of the meeting to the other attendees

Describing your Symptoms

The first step to getting the right treatment, is getting the right diagnosis which will be based on the description of the symptoms you share with the health professional you see.

Similarly, if you're already receiving treatment, any changes to or reviews of that treatment will be based on an assessment of your condition. So, the information you give the health professional is vital if they are to work with you to determine the care and treatment you need.

Have a look at the [Preparing for Meetings/Appointments](#)

Top Tips and Worksheets but in addition:

- Be honest about your symptoms – don't worry that your health professional will judge you – they're there to help.
- Don't just focus on any obvious rituals that you carry out – make sure you explain about your intrusive thoughts too.
- Are you using alternative treatments or alcohol to cope with your symptoms/ease your anxiety?
- What, if any, treatment have you had in the past? Was it helpful? Would you consider trying it again?
- What other mental or physical health issues do you have or are taking medication for that might be impacting on or impacted by your symptoms?
- Describe how the symptoms impact on your daily life – don't underplay the impact.

**Top
Tips**

What Treatment?

- Don't forget that the effective treatment for OCD/BDD and related disorders recommended by NICE is **Cognitive Behavioural Therapy (CBT) and/or medication**. If a different treatment is suggested ask for the reasons for that. Health professionals do not have to follow NICE guidance but if they are not doing so then they should tell you why they believe an alternative treatment might be clinically more beneficial. If you don't agree with them you could ask for a second opinion.
- If you are being prescribed medication your prescriber should give you information about the possible risks, benefits and any potential side effects (and what to do if they occur) so that you can make an informed decision whether to take the medication or not.
- You should **not** be put in the position of having to agree to take medication in order to get a referral for CBT.

For more information about treatment, you can get in touch with the OCD Action Helpline by emailing: support@ocdaction.org.uk or by calling: 0845 390 6232.

Self-Advocacy Worksheet 2:

Preparing for a Meeting/Appointment

Appointment Details

Date: *Place:*.....

The appointment is with:

.....

What is/are their role(s)/job title(s)?:

.....

Reason for the appointment:

.....

Questions/Points I want to raise/Symptoms I want to mention:

.....
.....
.....
.....
.....
.....

*Information I need to take with me (e.g. OCD Action's GP card;
Getting a Referral to a Nationalist and Specialist OCD Service)*

.....

Self-Advocacy Worksheet 3: Appointment Summary

Treatment/action plan:

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.....
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.....
.....
.....
.....
.....

*Who is responsible for the treatment/action
plan:*.....

.....
.....

*What is the timeframe for the treatment/action
plan:*.....

.....

*Date & time of the next
appointment:*.....

.....

Self-Advocacy Worksheet 5: CBT Summary

| Date Started | Date Finished | Number of Sessions & Frequency | Details of Therapist |
|--------------|---------------|--------------------------------|----------------------|
| | | | |
| | | | |
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| | | | |
| | | | |
| | | | |

Letter Writing Tips

Sometimes a formal letter works best as an effective means of being heard. The advantages of putting your request or concerns in writing is that there is a record kept of that request and you are also more likely to receive a formal written response. Obviously, if you don't get a response – chase it up and be persistent!

However, how many times do we write formal letters these days? It can be quite daunting to know where to start so we've given you some tips.

- 
- Keep it brief and to the point – you want the letter to be read so, try to keep it to a maximum of two pages and break it up into paragraphs.
 - It's fine to hand-write your letter if you don't have access to a computer.
 - Keep a copy for your records.
 - It can be a good idea to ask someone else just to read it through before you send it – just to make sure that you've been clear in what you're saying and asking for.

STARTERS: The name, title and address of the person who you are writing to in the top left-hand corner. Your address goes on the right-hand side at the top of the letter with the date a line or two below it.

ADDRESSING YOUR CORRESPONDENT: e.g. *Dear Mr Smith* – don't use first names, or a combination i.e. *Dear Joanna Trollope* or address a collective i.e. *Dear CMHT*. If you don't know the name of the person then it is *Dear Sir/ Madam*, in rare circumstances it might be 'To whom it may concern' but these are more likely to be statements rather than letters.

The style should look something like this:

*Dr Peeps, Consultant Psychiatrist,
Fallowfields Community Mental Health Team,
Social Services Area Office,
High Street,
Withington
M60 4PS*

My address

16 February 2018

Dear Dr Peeps,

KEEP TO THE POINT: identify the purpose of your letter – what do you want?

e.g. *I am contacting you to request a referral for specialist OCD treatment. / I am writing to you to make a formal complaint about my treatment at BLAH Hospital.*

REDUNDANCY – look at the content – is it all necessary, have you repeated the same word three times in the same sentence or have you made the same point twice?

AVOID USING UNFAMILIAR ACRONYMS/ABBREVIATIONS OR TECHNICAL JARGON:

rule of thumb is to write out in full first time with a bracket abbreviation next to it: e.g. Community Mental Health Team (CMHT), Obsessive Compulsive Disorder (OCD), Cognitive Behavioural Therapy (CBT) and from then on you can use the abbreviations as shown.

SPELLING: careful how you use a spell checker...

GRAMMAR: does it flow? Read it back to yourself out loud, put commas in where you have to pause for breath. Use paragraphing when you begin a new topic.

ENDINGS: these are rarely easy...try to keep your letter outcomes focused and positive, you will usually be waiting for them to make the next move ... variety of friendly endings but don't go over the top – 'kindest' (unless you are inviting the consultant to dinner next week) is inappropriate, also 'best' on its own.

Some ideas:

- *Would appreciate your help in resolving this matter*
- *With thanks*

With *Dear Mr/Miss* the standard exit is: *Yours sincerely*

With *Dear Sir/ Madam* it is: *Yours faithfully*

On both please note that *Yours* begins with a capital but the following word begins with a small letter.

COPIES: send copies of your letter to anyone you would want to be informed. Put 'cc' at the bottom of the letter and include a list of everyone you've sent a copy of the letter to.

Making a Telephone Call

If you're going to call to seek information or to self-advocate it's worth making some notes beforehand so that you're clear what you want to say and what you want from the call.

- State your name and what you need – be brief – it is often helpful to have a sentence or two written down for this opening.
- If the first person you speak to can't help you – ask to be put through to someone who can.
- If the person you need/want to speak to is not available – ask when they will be so that you can ring them then.
- Ask for the direct dial number of the person you want to speak to to avoid having to go through reception/another person each time.
- Ask for the name and position/role of everyone you speak to – write this information down – don't be afraid to ask people to spell names.
- Keep a record of the date, times, names and positions of the people you have spoken to and what was said. See our Telephone Log Worksheet!
- Try to remain calm and clear on the phone even if you are distressed and frustrated – be focused on your goal!
- Don't forget to listen!
- Always be polite – the person who answers the phone may be your gateway to the person who is responsible for making the decision you need and you may end up speaking to them often as you try to speak to the decision-maker – so, keep them sweet!
- If someone is going to pass on a message/ring you back – ask them when they will do that – write that down.
- If people don't ring you back or the situation is not resolved – ring again.
- If, when the person you've left a message for does ring you back, you're not ready to speak to them, arrange for them to ring another time so that you can be well prepared to speak to them – see the sheet on Communication Skills.

If you are unsatisfied with the result of the call:

- Ask why the person can't help. Write down the answer they give you – make it clear that you are doing this. Ask for them to put that decision in writing to you along with the reasons.
- Ask if there is another agency/person that may be able to help you.
- If the person you speak to is rude or unpleasant – ask to speak to their Line Manager.

Self-Advocacy Worksheet 6:

Telephone Log

Outgoing Phone Log

Date:

Person called:

Telephone

Number:

Was call answered?.....

Left message?.....

Person spoken with:.....

Title & organisation of person you spoke with:

Summary of conversation:

.....

.....

Action suggested:

Action agreed upon:.....

Deadline:

Incoming Phone Log

Date:

Person calling:.....

Telephone Number:

Title & Organisation of person calling:

Summary of conversation:

Action suggested:

Action agreed upon:

Deadline:

Improving Access to Psychological Therapies (IAPT)

Improving Access to Psychological Therapies (IAPT) services provide a wide range of talking therapies to people with anxiety & depression disorders (including OCD) across England. IAPT services are part of the NHS and are therefore free to access. They have been around since 2008 but many people who contact OCD Action through the Helpline seem unaware of them, as do their GPs. Part of the problem may be that many IAPT services are not called IAPT services but have a number of different names e.g. Wellbeing Norfolk & Waveney, Faversham Counselling Service, Mindsmatter (Lancashire) etc.

You should be able to find details about your local IAPT service on the NHS Choices website: www.nhs.uk

Staffing of NHS IAPT Services

Two types of psychological therapy practitioners are trained to deliver therapies in NHS IAPT services and who you see should depend on the severity of your condition:

- **High Intensity Therapists** trained in Cognitive Behavioural Therapy (CBT) for people with moderate and severe depression and anxiety disorders, and a range of other therapies as recommended by NICE.
- **Psychological Wellbeing Practitioners (PWPs)** trained in cognitive behavioural approaches for people with mild to moderate anxiety and depression. These approaches include guided self-help and delivering psycho-educational groups.

IAPT services may also have administrative staff, employment advisors, a GP advisor and links with other services such as housing, drugs advice and benefits.

Access & Waiting Times

In some areas you will be able to refer yourself to your local IAPT service, while in other areas you will need a GP referral.

OCD Action receives many calls and emails from people who are waiting a long time for treatment from their local IAPT service but the National Standards for waiting times for IAPT services say that 75% of people referred to IAPT services should start treatment within 6 weeks of referral, and 95% should start treatment within 18 weeks of referral.

Choice

It is important that people have a say in what kind of treatment they receive. This helps ensure the best health outcome for them. After your assessment your assessor should explain which treatment they are recommending and why they think it is suitable for you.

Therapies Available

IAPT services provide talking therapies recommended by the National Institute of Health & Clinical Excellence (NICE). Your IAPT service will always provide CBT but it may also offer all or some of the following:

- Couple therapy
- Counselling for depression
- Interpersonal Psychotherapy (IPT)
- Brief Psychodynamic Psychotherapy

The clinically-proven treatment recommended by NICE for OCD/BDD and related disorders is CBT and at your assessment you should be informed of this but given a choice of treatments. OCD Action has found that many people who contact us, who are waiting for treatment to start, are unsure what treatment they are waiting for and whether it will be one-to-one or in a group. If you're not sure please ask the person assessing you to explain and to put your treatment plan in writing.

Support During Treatment

Through OCD Action's Next Steps service a Helpline Volunteer can give you a weekly / fortnightly call to provide you with support while you're having CBT treatment. Our Helpline Volunteers aren't therapists, their role is to keep you motivated to complete the course and to do the homework you will be set. As many of our volunteers have OCD themselves they may well have had CBT and know what hard work it is.

Also, there is information on OCD Action's website about support groups across the UK and we have a useful resource called the CBT Checklist on the resources page which explains what should be happening in CBT sessions.

Stepped Care

NICE recommends a range of psychological therapies to treat people with depression and anxiety disorders. It also recommends that these therapies are used to provide a system of stepped care. This means that your treatment for OCD/BDD and related disorders should be reviewed and you should be referred onto more or less intensive treatment within IAPT services or to a different service if the treatment or intensity of treatment you need cannot be provided by your local IAPT service.

Rate your IAPT Service

You should be asked for your feedback once you have been assessed by your local IAPT service and a treatment plan has been agreed with you. You should then be asked to rate your satisfaction with the service once you have completed treatment with them. These are Patient Experience Questionnaires (PEQ).

Community Mental Health Teams (CMHT)

Community Mental Health Teams (CMHTs) are secondary care services found across the whole of the UK. Although the makeup of these teams is fairly consistent they may have different names such as the Community Recovery Team or Assessment and Brief Treatment Team, Recovery & Wellbeing Team or Complex Care Team.

Most people with OCD/BDD and related disorders will have mild symptoms and will be treated by their GP but some will have more severe symptoms that have a greater impact on their wellbeing and so will need to see a mental health professional. If your GP feels that this is the case then they will refer you onto your local Community Mental Health Team (CMHT) for an assessment and possible treatment.

A CMHT is a multi-disciplinary team of mental health professionals working with adults, often between 18 and 65. Child and Adolescent Mental Health Services (CAMHS) work with children and young people and often there are specific teams working with people over 65. In addition, there are some more specialist teams providing crisis support, assertive outreach, early intervention for psychosis or that have another specific care & treatment focus.

The mental health professionals most often found in a CMHT include:

- **Psychiatrist** – A psychiatrist is a medically qualified doctor with specialist training in mental health. Every CMHT will have a Consultant Psychiatrist and, in addition, may have a more junior doctor who is trained in psychiatry but has not yet become a consultant. A psychiatrist is often responsible for the prescribing and monitoring of medication.
- **Psychologist** – A psychologist within a CMHT may be a Clinical Psychologist which means they have a degree in psychology and another 3 years training in clinical psychology during which time they work with clients and learn how to give psychological treatments. They also help other members of the team to work psychologically with their clients. Although they are trained to use several models of psychological therapy (usually Cognitive Behavioural Therapy plus at least one other model e.g. psychodynamic/systemic) they do not necessarily have specialist knowledge and experience of CBT.
- **Community Psychiatric Nurse (CPN) or Mental Health Nurse (MHN)** – A nurse trained in mental health who provides emotional and practical support to an individual. They can give medication and monitor its effects.
- **Occupational Therapist (OT)** – An OT provides assessments, information and practical support around self-care, everyday tasks and work and leisure to help an individual live independently.
- **Social Worker** – Social workers bring a social perspective to the team's working. They help people to talk through their problems, give them practical advice and emotional support and provide some psychological treatments. They are often able to give expert practical help with money, benefits and housing issues.

CPNs, OTs and Social Workers often have very similar duties and responsibilities within a CMHT and all can be key workers or **Care Coordinators**.

Referral & Assessment Process

It might vary across the UK whether a CMHT will accept a referral from a health or social care professional but they will always accept a referral from a GP. If the CMHT accepts the referral it will arrange for you to have an assessment. There are several different methods of assessment but all involve asking detailed questions to find out how much of your day-to-day life is affected by obsessive-compulsive thoughts and behaviour. The assessment may take place over a number of appointments and with a number of different health & social care professionals.

According to NICE, before the assessment starts, health and social care professionals should explain:

- ❖ what an assessment is, what happens and how long the appointment will last.
- ❖ what information they may have to share with others, in what circumstances, and how they will keep the information about you safe
- ❖ that any decision about your treatment and care will be a joint one made by you and health and social care professionals.
- ❖ that you can refuse permission for any other member of staff, for example a student, to be present.

During the assessment, you should be given enough time to talk about your problems, with time at the end for you to ask questions. If you are given a diagnosis, this should be clearly explained and you should be given a booklet or leaflet about it. The healthcare professional should discuss different treatments and give you information about each. You should also be offered time to talk after the assessment, especially if any sensitive issues were discussed. If you are unhappy about the assessment and diagnosis, you should be given time to talk about this and offered a second opinion.

In most cases, copies of all correspondence about your diagnosis, treatment and care between your health and social care professionals and other professionals should be sent to you, unless you decide against it.

If as a result of the assessment the CMHT feel you need further support from them then they should work with you to develop a **Care Plan** and you will be allocated a key worker or **Care Coordinator**.

Making a Complaint

Most concerns and complaints you'll have with service providers can be best resolved informally but if you have attempted that and your efforts have been blocked or things have not changed you may feel that your only option is to make a formal written complaint. You might feel reluctant or afraid to do this, particularly if you have been refused a service, but if you are unhappy with the way you have been treated and the decisions made in your care you have the right to complain.

You can use our Letter Writing Tips resource and the Complaint Letter Writing Worksheet in this toolkit. Make sure you make your complaint within 12 months of the incident/action/decision that you wish to complain about.

Complaint procedures vary from organisation to organisation but more usually they have a staged process with time limits within which the service will acknowledge and respond to your complaint in writing. If the organisation is unable to meet those time limits they should inform you of that.

As part of the investigation of your complaint the allocated investigator may well ask to meet/speak to you – it is your choice as to whether to do this or not. In the case of complaints to an NHS health trust the investigator will be a senior manager from within the organisation.

PALS: Patient Advice & Liaison Services – these services form part of all NHS hospital trusts and they're there to support you with any concerns and issues you have with the hospital services you are receiving. They can help you make complaints.

What can I expect if I complain?

You should:

- Have your complaint acknowledged and properly looked into
- Be kept informed of progress and told the outcome
- Be treated fairly, politely and with respect
- Be reassured that your care and treatment will not be affected as a result of making a complaint
- Be offered the opportunity to discuss the complaint with a complaints manager
- Expect appropriate action to be taken following your complaint

NHS England

The NHS Constitution

The NHS Constitution sets out your rights as a patient, and explains the commitments the NHS has made to providing you with a high quality service. Organisations providing NHS care must take account of the NHS Constitution when treating you, so you may find it helpful to refer to it if you are thinking about making a complaint.

Unhappy with the outcome of your complaint?

If you are not happy with the way your complaint has been dealt with by the NHS health trust's complaints service and would like to take the matter further, you can contact the Parliamentary and Health Service Ombudsman (PHSO) which makes final decisions on unresolved complaints about the NHS in England. It is an independent service which is free for everyone to use. To take your complaint to the Ombudsman, visit the PHSO website or call: 0345 015 4033.

If you don't want to complain to the NHS health trust about one of their services you could complain to your area's Clinical Commissioning Group (CCG). If you're unhappy with the response you receive to your complaint to the CCG and feel that your issue has not been properly addressed then you can complain to NHS England about them.

Top Tips on Writing a Formal Complaint about an NHS Service

- Follow our Letter Writing Tips!
- Follow your NHS health trust's complaints process - it should be on their website and if you don't have access to the internet ask for a copy to be sent to you.
- Make it clear in your letter that you are making a formal complaint.
- Include in your letter any steps you have taken to resolve the issue informally.
- Be brief and concise - only include information that is relevant to the current issue - what happened, the name and role of who was involved - remember to include dates and make reference to and enclose any relevant documents.
- Explain how what has happened or the decisions made have impacted on you and your OCD/BDD.
- Be polite! You may well be angry and upset but it is best not to use the complaints process to threaten a member of staff or to use offensive language.
- Be clear about what you want to happen as a result of your complaint but be realistic! It is unlikely that the Trust will agree to sack anyone on the basis of your complaint or provide you with a live-in therapist. You will not gain financial compensation as a result of a formal NHS complaint. But it is reasonable for example to ask for an apology for poor practice and communication, for a decision to be reconsidered or a procedure to be changed.

Self Advocacy Worksheet 7 – Complaint Letter Writing Worksheet

CONTACT OF PERSON & ADDRESS TO SEND COMPLAINT TO

(Check complaints procedure for this)

DATE

Dear NAME

I am writing to make a formal complaint aboutWHO? – A PERSON/A SERVICE?

WHAT HAPPENED? GIVE SPECIFIC DATES, PLACES or MAKE REFERENCE TO LETTERS / DOCUMENTS YOU RECEIVED / SENT

HOW HAS THIS IMPACTED ON YOU?

WHAT HAVE YOU DONE TO TRY TO RESOLVE THIS ISSUE INFORMALLY? WHAT WAS THE OUTCOME?

WHAT DO YOU WANT IN RESPONSE TO THE COMPLAINT? E.g. an apology? A service? A review of a decision?

IF THE COMPLAINT PROCEDURE HAS TIMESCALES FOR RESPONSES YOU COULD MAKE REFERENCE TO THEM

HOW DO YOU WANT TO BE CONTACTED? E.g. email, letter?

I look forward to hearing from you in due course.

Yours sincerely/faithfully – see Letter Writing Tips!

SIGNATURE

CC – who else are you sending the letter to? E.g. your GP – put their name here

Feedback

Did you find the following useful?

Accessing Treatment Worksheet: YES NO

Why?.....

Advocacy Planning: YES NO

Why?.....

Worksheet 1: YES NO

Why?.....

Communication Skills: YES NO

Why?.....

Preparing for Meetings: YES NO

Why?.....

Describing Your Symptoms: YES NO

Why?.....

What Treatment?: YES NO

Why?.....

Worksheet 2 - Preparing for a Meeting/Appointment: YES NO

Why?.....

Worksheet 3 - Meeting/Appointment Summary: YES NO

Why?.....

Worksheet 4 - Medication Summary: YES NO

Why?.....

Worksheet 5 - CBT Summary: YES NO

Why?.....

Letter Writing: YES NO

Why?.....

Making a Telephone Call: YES NO

Why?.....

Worksheet 6 - Telephone Log: YES NO

Why?.....

Improving Access to Psychological Therapies (IAPT): YES NO

Why?.....

Community Mental Health Teams (CMHT): YES NO

Why?.....

Making a Complaint: YES NO

Why?.....

Worksheet 7 - Complaint Letter Writing Worksheet: YES NO

Why?.....

We would really value your feedback on this toolkit. Please fill out the feedback form and post it back to OCD Action at the following address:

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London, EC1V 7ET