

A blue circle containing the text "Rethink Mental Illness." in white, stacked vertically.

Rethink
Mental
Illness.

Physical health.

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**What carers,
families and
friends need
to know**

Introduction

People with mental illness have just as much right to good physical healthcare as anyone else. But too often this doesn't happen. We regularly hear from our members that physical health can be overlooked by health professionals. We also know that carers, families and friends can be frustrated when they try and get physical health care for the person they support.

We carried out two surveys to find out what problems people face when trying to get this support. The first survey was for carers, families and friends and we had 184 responses. In the second survey we heard from 389 people who use mental health services about their experiences of physical health care.

We found that:

- Nearly 90% carers have concerns about the physical health of the person they care for.
- Over 40% of people who use mental health services have experienced problems accessing physical healthcare.
- Only 1 in 4 carers get the support they want from health professionals.

- 1 in 3 carers are worried about the side effects of mental health medication, such as weight gain.

We also met with carers to find out what physical health information they would find useful. They worked with us to develop this guide for families and friends. It can help carers get better physical healthcare for the person they support. It contains tips on medication, preparing for GP appointments and sharing information with professionals.

This guide helps people get the most from health services. It does not cover people who are not currently accessing any services. However we would like to see more support available for this group. We have made recommendations on this and other physical health issues in our policy paper *Physical health: supporting family and friends in a caring role*. This includes further information from our survey. It is available on our website www.rethink.org.

This guide has been produced as part of a project funded by NHS London.

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What support should people be getting and from who?



There is a lot of guidance that says what physical healthcare people with mental illness should receive. Different professionals provide this support at different times.

From a GP

Every year GPs should check the physical health of people with mental illnesses such as schizophrenia, schizoaffective disorder, bipolar disorder and psychosis. In order to get this annual check, people need to make sure they are on the GP practice's mental illness register.

Practices will have registers for a number of different health conditions to make sure people get the checks and care to which they are entitled.

Starting medication

Before a person starts any medication for a mental illness, health professionals should do a full set of physical health checks. This is true no matter where they are prescribing the medication. They should then repeat these tests after three months to monitor the impact of the medication on a person's physical health.

If there is a negative impact, health professionals should offer support or possibly review and change the medication.

From a care coordinator In hospital

Some people in contact with mental health services might have a care coordinator. This could be because they are under the Care Programme Approach (CPA) or an Early Intervention service. Care coordinators should help the person they support to monitor and organise their care, including access to physical health services. They should write a plan for the person's care and treatment and review it regularly. As part of this review, the care coordinator should ask about any physical health concerns the person might have. They can then include these concerns in the plan and share a copy with the person's GP.

When someone goes into hospital or any other inpatient setting, they should have a full physical health check. Guidelines recommend that staff should gather information about what medication the person is taking. This includes physical health medication.

They should also include all physical health needs into the person's treatment plan. On discharge staff should share this information with the person's GP and other relevant professionals.



Visiting the GP surgery



For many people, their GP is a real source of support for both their physical and mental health needs. But other people might be nervous going to their GP surgery. They may be worried their GP won't believe them if they talk about physical health concerns, or might struggle to make appointments early in the morning because of their medication.

Under the Equality Act 2010 GP surgeries must make adjustments so that everyone can access them. See our top tips if you are booking appointments for the person you support or if you want to raise concerns with your GP.

People with mental illnesses such as schizophrenia, schizoaffective disorder, bipolar disorder and psychosis should have an annual physical health check. It is not only for people who take medication, but people do need to be on the practice's mental illness register.

People should receive an invitation to attend the check once a year. If the person you support has not received an invitation, you can ring and make an appointment.

The GP or practice nurse should share the test results with other people involved in the person's care, for example their care coordinator

You could get a copy of the annual physical health check results, if the person you support has agreed for them to be shared with you.

and/or psychiatrist. You could also get a copy of the results if the person you support has agreed for them to be shared with you.

Unhappy with your GP?

In some cases people might have had a bad experience with their GP. Some of our members tell us their physical health concerns are overlooked if health professionals assume they are linked to their mental health.

If you or the person you support are unhappy with a GP, you can ask to be referred to a different doctor in the practice. You can also change to a different GP surgery if it is open to new patients and covers the area you live in.

What if the person I support is not registered with a GP?

It is important to register with a GP to access local health services and annual health checks. We encourage people to register if they have not already done so. You can find out which surgeries in your area are accepting new patients on the **NHS Choices** website www.nhs.uk.

Top tips

- Book a double appointment to have more time with the GP
- You don't have to let the receptionist know why you are making an appointment
- Ask if it is possible to book appointments later in the day if medication makes it difficult for the person you support to get up early
- Check if there is a quiet area to wait
- Ask if you can be included in appointment reminders sent to the person you support if appropriate
- Write a list of key things to raise before going to the appointment
- You can accompany the person you support in an appointment if they want
- Make notes in the appointment so you have a record
- Check that the person you support is on the practice's mental illness register



Medication and side effects



Some medications for mental illness can have side effects which impact on physical health. This might include sudden weight gain or a lack of energy. While this won't happen in every case, this section deals with some of the most common side effects.

When a psychiatrist, GP or other health professional prescribes medication they should provide clear information about the medication, including possible side effects. However in some cases this doesn't happen and people do not know what side effects to expect.

Before a person starts any medication for a mental illness they should have a full set of physical health checks e.g. blood pressure. The person prescribing the medication should make sure these tests take place so you can ask whether this has been done.

There are some key points you can raise if the person you support takes medication. These include:

- Asking about side effects and what can be done to reduce their impact
- Make sure the person prescribing knows about any other medication the person is on as they can react with each other
- Ask how the medication may interact with over-the-counter medication, alcohol, tobacco or certain foods
- Check when the medication should be reviewed

Common side effects

The side effects people experience vary depending on the medication and their own reactions to it. These are some of the most common ones to look out for:

- Weight gain or loss
- Fatigue and lack of energy
- Reduced sex drive or difficulties having sex
- Constipation
- Dry mouth
- Problems sleeping
- Dizziness

It can be useful to keep a record of any physical health symptoms so that health professionals can see if they are linked to medication.

If someone is taking **clozapine** or **lithium**, they should have regular blood tests on top of their annual physical health check. These medications can, in rare cases, have serious side effects so it is important these regular tests take place.

Concerned about side effects?

If you or the person you support are concerned about side effects, it's best to discuss them with a psychiatrist, GP or pharmacist. They should offer support and advice in managing side effects. They might also check the dosage is correct and in some cases may change medication.

Reviewing medication

A medication review is a chance for a person taking medication to discuss the impact of this medication and its side effects on them. This should happen regularly, preferably annually, with either the GP or psychiatrist. The review should take into account all the medication the person is taking.

In some cases a medication review might form part of an annual physical health check or a Care Programme Approach review. Some local pharmacies also offer medication reviews.

We have a range of factsheets on different types of medication available at www.rethink.org/factsheets or by calling 0300 5000 927.

Healthy lifestyles



Living with a mental illness can make it difficult to follow a healthy lifestyle. Low energy levels as a result of medication can make regular exercise hard. This section looks at some important areas of healthy living and how you can support the person you care for to access health services.

Smoking and alcohol

Smoking and alcohol use can interfere with mental health medication. Smoking reduces the levels of medication in the blood. This means people might need higher doses for the medication to have the same effect. It is therefore important to check with a psychiatrist or GP before stopping smoking.

There is a lot of support available for people who want to quit smoking. Their GP should be able to offer support and advice.

Help is also available from:

NHS Smokefree
www.smokefree.nhs.uk
0800 022 4332

Some professionals advise that people don't drink if they take certain medications as alcohol can also interact with medication. More information on this should be available in the information leaflet that came with the medication. Alternatively you could check with the person who prescribed the medication.

Healthy teeth and gums

Some medications can have an impact on a person's oral health. It is therefore very important that people attend regular check ups with a dentist. Details of your local dentist are available from:

NHS Choices – www.nhs.uk

If your friend or relative is anxious about going to the dentist they should let the dentist know beforehand. They can also take you with them if they would like.

People on certain benefits may get free dental care, or help with their costs. You can find out more at www.nhs.uk/NHSEngland/Healthcosts or by calling the **Health Cost advice line** on **0845 850 1166**.

Diet and exercise

Weight gain can be a serious side effect of medication for some people. Regular exercise and a healthy diet are important but it can be difficult to manage this without support.

A GP or care coordinator should offer advice and information on diet and nutrition and may know of exercise groups or facilities locally. Some areas have 'health trainers' who offer one to one support to help people live more healthily. Your GP or mental health worker should know if these are available in your area, or you can look on your council's website.

You can also ask your GP or NHS services if there are healthy living peer support or community groups available locally that might help.

Sexual health

Although people affected by mental illness are a high risk group for some sexual health problems, mental health professionals often do not provide advice and information. If you or the person you support have concerns you should raise them with a GP. Advice is also available from sexual health charity FPA (www.fpa.org.uk or **0845 122 8690**). You can find details about local sexual health clinics and support services via NHS Choices www.nhs.uk.

Feet

There is an increased risk of diabetes among people with mental illness. If the person you support does have diabetes then regular foot checks are really important. Diabetes can cause poor circulation and reduced feeling in the feet. If you have any concerns, you can always raise them with a GP, who might refer you to a foot specialist.

It's important that as a carer you look after your own physical health. You can ask your GP or council what support is available locally, including carers' assessments.



Being in hospital



People can find it difficult to manage their physical health if they are in an inpatient environment. But they have the same right to access physical healthcare as people being treated in the community.

Physical health while in an inpatient or secure hospital

When someone goes into hospital they should have a full physical health check. This includes getting information on all medications the person is taking. It might be helpful to keep a list of medications for the person you support so you can share this with professionals. They should include any physical health concerns in the person's treatment plan.

If someone is in hospital and under the Care Programme Approach (CPA), they should still have regular reviews. They should continue to have their physical health checked and medication reviewed annually. People should also have access to primary care, such as a GP or dentist.

Some trusts offer support with travel costs for families and friends if the person you support is in an inpatient setting out of your area. You should ask your trust if they are able to help.

Mental Health Act and Community Treatment Orders

If someone is in hospital under the Mental Health Act, they should still have access to regular CPA reviews and primary care as well. On discharge, they may be under something called a Community Treatment Order (CTO). This means someone receives treatment in the community with certain conditions.

If they do not meet these conditions, a doctor can recall them to hospital if



necessary. Professionals use CTOs if there are concerns about the person continuing to get treatment.

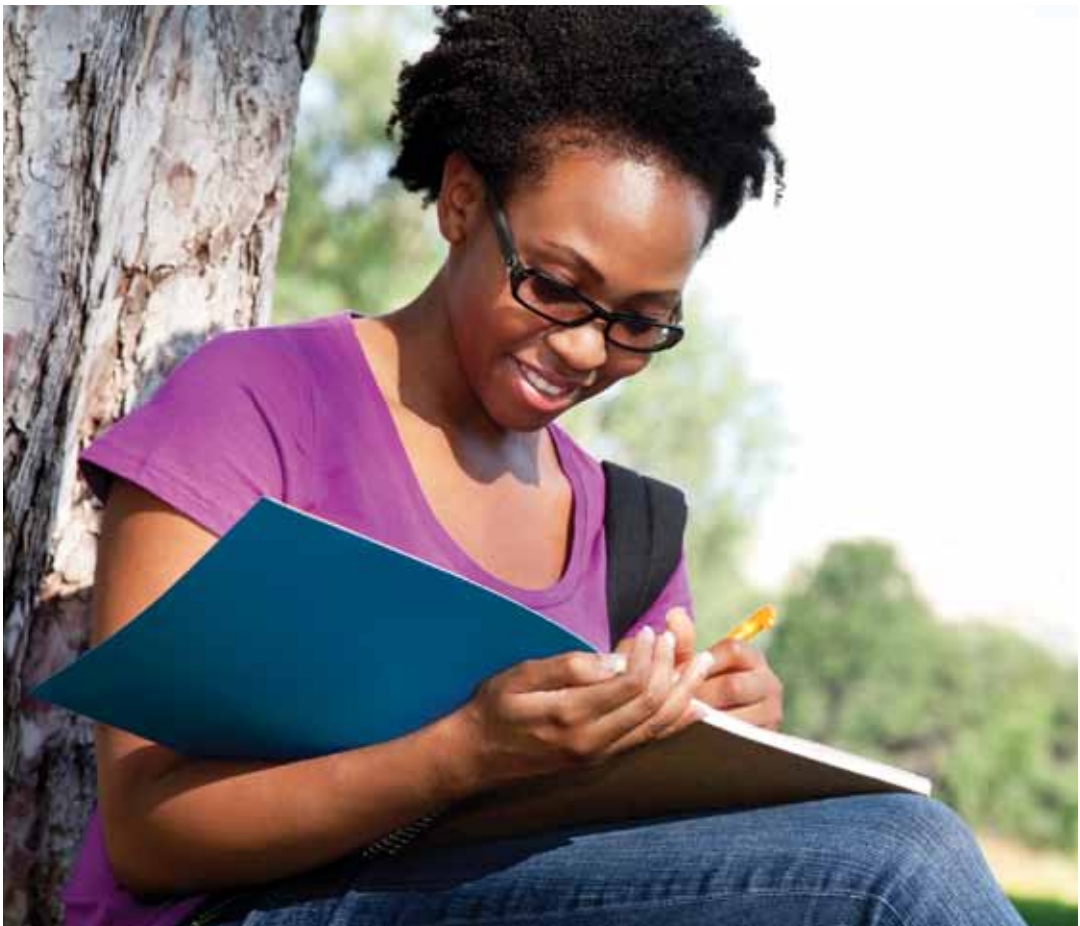
If a person is under a CTO they should have a care plan that sets out their treatment and includes any physical health concerns. Their care coordinator should reviewed this plan regularly.

You can find further information in our factsheets on 'Care and Aftercare' and 'Nearest Relative' which are available free from www.rethink.org/factsheets or by contacting 0300 5000 927.

Sharing information with professionals



We often hear from families and friends that confidentiality can be a barrier when they engage with professionals. Many people are frustrated at how they are excluded from the care of the person they support, even when that person has allowed information to be shared with them.



Confidentiality

There are many reasons someone might not want their family and friends to have details of their condition or treatment and this should be respected. Even if a doctor can't share any information with you they should listen to concerns and information you give them. They should also record the information you give them in the medical notes.

If the person you support is in hospital under the Mental Health Act, you may be their 'Nearest Relative'. This is a legally defined role with certain rights and is different to next of kin. It does not give you any additional rights around sharing information about the person you support if they have not agreed to share this with you.

In some cases professionals can exclude carers even when there is consent to share information . It is always best if the person you support writes down their wishes about sharing information and professionals should include this in care plans or records.

You can find further details in our 'Carers and confidentiality' or 'Nearest Relative' factsheets, available from www.rethink.org/factsheets or on 0300 5000 927.

Advance statements

An advance statement is a document that someone draws up to let people know their preferences about care, treatment etc. If they then become too unwell to communicate these wishes, there is a record for people to refer to. They are not legally binding but it is good practice for doctors to follow them.

An advance statement might be a useful place for people to record information about their physical health i.e. medication or health conditions. It can also be an opportunity for them to express preferences about who their information is shared with. You can find a template in our 'Advance Statement' factsheet.

Appointments and reminders

To make sure the person you support doesn't miss any appointments you might ask to receive any reminders they get, as long as they are happy with this.

You can also help them prepare for appointments by making a list with them of key things they want to raise. If this is written down beforehand it can be a prompt in the appointment and could even be handed to the professional.

Complaints and advocacy



Unfortunately some people do not get the physical health care and checks that they should. In this situation you might need to make a complaint, or to approach other agencies within the health service.

Patient Advice and Liaison Service (PALS)

Local PALS are the best first starting point if you have any concerns about your local services. They might help you resolve a less serious complaint or can offer information and advice on making a formal complaint.

You should be able to find out the details of your local PALS through NHS services.

Trust policies

Mental health trusts should have policies that set out their processes around physical healthcare and what people should expect. If you are concerned that the person you

support is not getting the right care you could request a copy of the policy and check.

You should be able to find this information on the trust's website or you can ask PALS. You can also get copies from either the Publications or Freedom of Information teams in the trust.

Complaints

All services have a complaints procedure outlining how you can make a complaint. It is important to make clear in your communications that it is a complaint so the correct procedure is followed. You should keep a note of when things go wrong so you can include this in your complaint.

You can find more information in our 'Complaining about the NHS or social services' factsheet at www.rethink.org/factsheets or on 0300 5000 927. Alternatively the local **Independent Complaints Advocacy Service (ICAS)** should be able to help – you can get contact details from PALS.

If you are unhappy with the outcome of your complaint, you can refer it to the **Parliamentary and Health Service Ombudsman (PHSO)**. This is an independent body that looks at complaints against the NHS.

Advocacy services

Advocates work to ensure that people get the care they should. Some advocates work with people

in hospital under the Mental Health Act (Independent Mental Health Advocates) or the Mental Capacity Act (Independent Mental Capacity Advocates). If someone is under the Mental Health Act they have a right to an advocate.

The mental health service should provide them with contact details for a local advocacy service. Other advocates cover general case work and might be provided by the local authority, or by voluntary organisations. Advocates could help the person you support get access to the physical health care they are entitled to.

You can find a list of advocates at Action for Advocacy at www.actionforadvocacy.org.uk or on **0207 921 4395**.





Other useful information



Rethink Mental Illness

We have a range of free factsheets that cover a number of the issues raised in this guide. All the factsheets can be downloaded from www.rethink.org/factsheets or requested from 0300 5000 927.

If you have a query that has not been covered in this guide, you can always contact the Rethink Advice and Information Service on 0300 5000 927.

We have also produced a Good Health Guide for people using mental health services. It contains tips and information on looking after your physical health. It can be accessed at www.rethink.org/phc.

National publications

There are a number of guidelines that outline best practice for physical health care for people affected by mental illness:

NICE guidelines

Schizophrenia – www.nice.org.uk/CG82

Bipolar disorder – www.nice.org.uk/CG38

Royal College of Psychiatrists standards for inpatient and forensic services

www.rcpsych.ac.uk

There are a number of surveys and audits that monitor how trusts are performing across the country. These include:

Care Quality Commission (community mental health survey)

www.cqc.org.uk

National Clinical Audits (prescribing and schizophrenia)

www.rcpsych.ac.uk

Health organisations

NHS Choices: www.nhs.uk

NHS Smokefree: www.smokefree.nhs.uk

Drinkaware

Facts and advice about alcohol.

www.drinkaware.co.uk

Addaction

National specialist drug and alcohol treatment charity.

www.addaction.org.uk

FPA

National sexual health charity offering advice and support.

www.fpa.org.uk

Terence Higgins Trust

Information, support and advice on HIV and sexual health.

www.tht.org.uk

Diabetes UK

Advice and information on diabetes.

www.diabetes.org.uk

Macmillan Cancer Support

Providing practical, medical and financial support for people affected by cancer.

www.macmillan.org.uk

British Heart Foundation: information on heart health.

www.bhf.org.uk

Who we are

Rethink Mental Illness is a charity that believes a better life is possible for millions of people affected by mental illness. For 40 years we have brought people together to support each other. We run services and support groups that change people's lives and challenge attitudes about mental illness.

We directly support almost 60,000 people every year across England to get through crises, to live independently and to realise they are not alone. We give information and advice to 500,000 more and we change policy and attitudes for millions.

We can provide details of the information sources we used to create this guide. Call us on 0300 5000 927 Monday to Friday between 10am and 1pm or email advice@rethink.org



Rethink Mental Illness is a partner in:



let's end mental health discrimination



**Leading the way to a better
quality of life for everyone
affected by severe mental illness.**

For further information
on Rethink Mental Illness
Phone 0300 5000 927
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www.rethink.org