

Improving lives together



Carers, Families and Friends Guide

England and Wales

Book 2



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Introduction

Cygnets' purpose is to make a positive difference in the lives of the individuals we care for, their loved ones and all those who work with us. Caring for people can be an opportunity to experience the joy that being compassionate can bring, but it can also be a challenging and stressful experience.



The term “carer” will be used throughout to encompass family, friends and other carers.



Making sure that carers are included?

We are committed to making sure that carers are involved and included along every step. Soon after the service user who you care for is admitted to a ward, you should be given the opportunity to discuss your own experience of and concerns about their health and wellbeing, and to provide any information that you think may be helpful to their treatment. A hospital admission can be a distressing experience and we recognise this is a difficult time and hope that the information this booklet will offer some support. You are always welcome to email: Family&Friends@cygnethealth.co.uk

Helping with Admission

Knowing how best to support the service user you care for can be challenging, especially if you see them experiencing acute distress, self-harm, changes in their behaviour or suicidal thoughts.

These are some key things to keep in mind during these times:

1

It may be useful to note the helpful and not-so-helpful approaches you have already tried in supporting the individual.

2

Sometimes, it is valuable to understand mental health diagnoses.

3

Keep a note of medication, changes to treatment and any questions you may have for the professionals involved in their care.

4

Sometimes keeping a diary of all appointments and meetings can be helpful.

5

When possible, continue to do shared daily activities with you.



Mental health charities can provide information on how best to support individuals. Unfortunately, however, there is no “one size fits all” solution.

Service users and residents at Cygnet are actively encouraged to invite individuals from their social network, where they feel appropriate, to various parts of their care planning. This may include:

- > Attending ward rounds
- > Attending Care Programme Approach (CPA) meetings
- > Attending Managers Hearing Meetings and Tribunals
- > Attending health appointments
- > Providing history / background information about your family member / friend
- > Requesting or agreeing to home visits
- > Engaging with family sessions or assessments with either psychology or occupational therapy
- > Attending Family, Friends & Carer events
- > Meeting your family / friend during the agreed leave



Consent and Confidentiality

All staff working in Health or Health and Social Care services are bound by law and professional codes of practice to a duty of confidentiality to their patients and to carers. We may not always receive consent from your family member to share information with you, but we can always listen to you.

Carers can understandably find it frustrating when they would like to know more about the support the person they care for is receiving, and they are refused information. There may be some things the person you care for does not wish us to share or involve you with. Where this is the case, we will do our best to support you in any way that we can without breaching confidentiality or going against the individual's wishes.

When can confidentiality be broken?

Any decision to break confidentiality must always be made in the best interest of the service user or resident to achieve the best possible outcome for them. It is essential that staff explain to you how and why the decision to breach consent is in the service user or resident's best interest. Where the service user withholds consent or lacks capacity and cannot express their wishes clearly, confidential information can only be disclosed in exceptional situations, such as where the individual's or others' health and wellbeing is under serious risk, or where there is a public interest or legal reason for disclosure without consent. Similarly, a carer's confidentiality can only be broken in exceptional circumstances such as risk to their own or others' health and wellbeing, public interest or for legal reasons.

Finding the Balance

Cygnnet recognises the vital contribution that so many carers make. We know that Carers are more likely to identify the subtle changes at an early stage of illness or relapse, as they know the individual when they're well. The information you can provide often be crucial.

Cygnnet acknowledges wherever possible, communication between staff and carers must start as early as possible. Staff will avoid professional jargon and communicate clearly. In most situations, locations will ensure face-to-face communication occurs in order to develop a mutually trusting and beneficial working relationship.

When an individual is not consenting to share information, a staff member might say to a carer: What sort of things do you want to know? I can talk about this but not that. I can't talk about your relative but we can talk about general aspects. For example, we might talk about why people who appear to talk to themselves might be doing that.

Principles of Best Practice

Staff should seek the service user / resident's views on sharing information as early as possible. This will usually be during assessment or admission.

This is the time when it is most likely the service user will refuse permission. This may be because they may be very unwell, feel betrayed by their carer, or be angry about the carer's role in their assessment, move, or possible detention.

There will be a clear understanding that sharing information will need to be re-visited. Even if permission to share information is refused at this point, staff must still give general information, discuss the carer's concerns or fears and signpost them to carer's support service.

Deciding what information is general and what is personal will be a clinical judgement in each case.

The same principle of confidentiality applies to information given by carers.

Recovery

When we talk about providing recovery-oriented services, we mean services that:



Are person-centred, collaborative and respectful



Promote self-management and self-determination



Work in equal partnership with the service user and carer



Promote optimism and hope



Recovery will look different for each individual and across each of our service types.

In all of these situations it is important to us that the carer is involved in how we are delivering recovery oriented care.

Informal Patients

An informal patient is someone who is in hospital for mental health care by choice. They are not detained under the Mental Health Act (sometimes called being "sectioned").

Being an informal patient means the person still has control over their care. They can:

- > Be involved in decisions about their treatment
- > Say yes or no to support offered
- > Leave the hospital if they wish

Care should feel like something done with the person, not to them. The focus is on working together, building trust, and supporting what matters to them.

How this is different from being detained

Some patients are in hospital under the Mental Health Act, which means there are legal restrictions in place. Informal patients have agreed to be in hospital. This means they are not under the same restrictions, and they have more freedom to make their own choices about staying or leaving.

If someone wants to leave

If an informal patient says they want to leave, this will usually be talked through with them. Often, it's about understanding what's behind that feeling whether something isn't working, or whether more support is needed.

In most situations, the person is free to leave. If there are serious concerns about their safety, or the safety of others, staff may need to look at this more closely and consider a Mental Health Act assessment. This is about making sure the person is safe, not about taking control away from them.

Frequently Asked Questions (FAQs)

Can an informal patient be made to stay?

No people who are informal patients are free to leave. If there are serious concerns about safety, staff may need to review the situation and consider next steps.

Will I be told if my relative wants to leave?

Where the person has agreed, staff will keep carers informed and involved in important decisions.



Hospital Admissions

At times, the individual you care for may require a stay in hospital. **A stay in hospital is only considered when the individual you care for has been assessed, and it is not considered appropriate for them to be treated at home.**

This is when the person you care for is in the **most acute and vulnerable stage of their illness**. The aim of any admission is to aid recovery, helping a person to return to everyday life by finding the right treatment for them.

Hospital admissions are described as either formal or informal.

Although most mental health problems are successfully managed in the community, some people need a stay in hospital. People are admitted to hospital either informally or under a section of the Mental Health Act (MHA). An informal patient can leave the hospital at any time and their movements are not generally restricted.

If your family member / friend has been detained, they will have to stay in hospital until the doctors or a Mental Health Tribunal decide otherwise.

Service Users staying in hospital under a section are not able to leave hospital without permission. As the mental health of the individual you care for begins to improve, they may be allowed time off the ward. This is known as Section 17 leave and / or weekend leave, when they may be able to return home. Please speak to a member of staff for more information.

You still have the right to visit. Visiting arrangements depend on the hospital, so check visiting hours with our staff.

In some cases, the individual may refuse visitors, and hospital staff will respect the service user wishes. If you're unable to see your relative, staff should explain why.

With permission from the service user, doctors may discuss the treatment plan with you. You can also raise concerns or worries with the doctors and nurses on the ward.

The most common mental health sections used are:

- > Section 136 is where a vulnerable person is thought to be suffering from a mental disorder, a police officer can remove them from a public place to a place of safety for up to 24 hours to allow for formal assessment under the Mental Health Act
- > Section 2 admission for assessment and treatment in hospital up to 28 days
- > Section 3 admission for treatment in hospital for up to six months

The Nearest Relative

The Mental Health Act gives particular rights to the 'Nearest Relative' of the person who has been detained.

Who is the Nearest Relative?

Nearest Relative (NR) is not the same as next-of-kin and has a legal definition. "Nearest Relative" is the legal term currently used in the Mental Health Act (1983). It gives certain rights to both the patient and the person identified as their nearest relative. The law is changing, and over time this role will be replaced by the "Nominated Person". This is intended to give people more choice about who they would like to support and represent them. For now, the "Nearest Relative" role still applies, and nothing changes in how you are involved. The move to the "Nominated Person" will happen gradually, likely between late 2026 and 2029.

The Nearest Relative is the person appearing highest in the following list if over the age of 18 and living in the UK (being the eldest where there is more than one):

- > Spouse / Civil Partner
(Partner if living together over 6 months)
- > Son or Daughter
- > Father or Mother
- > Brother or Sister
- > Grandparent
- > Grandchild
- > Uncle or Aunt
- > Nephew or Niece
- > People who have lived with the detained person for over five years.



There are some exceptions to this rule: if you are a relative of the detained person and normally live with them or provide their care, you will be defined as their Nearest Relative.

The legal Nearest Relative can appoint someone else to act as Nearest Relative, who takes on the rights of this role. A Court can also appoint an acting Nearest Relative under certain circumstances.

Staff at the hospital will be able to help you understand whether you are the legal Nearest Relative to the person you care for.

What rights does the Nearest Relative have?

As the Nearest Relative, if the person you care for becomes seriously unwell and is unwilling to seek hospital care, you can:

- > Ask an Approved Mental Health Professional (AMHP) to assess whether your relative needs to be admitted against their wishes (compulsory admission)
- > Apply for a compulsory admission yourself

If an application is made for your relative to be admitted to hospital for assessment (section 2), you have the right to:

- > Be informed about the admission

If an application is made for your relative to be admitted to hospital for treatment (section 3), you have the right to:

- > Be consulted before the admission
- > Object to the person being detained.



What is the Mental Health Act?

The Mental Health Act 1983 (further amended in 2007) is the law in England and Wales which sets out when a person with a 'mental disorder' can be admitted, detained and treated in hospital against their wishes either for their own health or safety, or for the protection of other people. Before anyone can be detained under the Mental Health Act, their Nearest Relative should normally be contacted.

The Mental Health Act has lots of sections related to the different circumstances under which a person can be detained.

Sometimes a service user with a mental illness might not be able or willing to be involved in decisions about their treatment because of their illness. If, without this treatment, there is thought to be a risk to the service user health or safety or the safety of others, the Mental Health Act is used to ensure they receive the necessary care.

The Mental Health Act represents a careful balance between the individual rights of patients and society's responsibility to protect them and others from the harm a mental disorder can cause.

There are **five 'guiding principles'** that mental health professionals must consider when they take a **decision to detain or treat someone under the MHA**:

1

Least restrictive option and maximising independence: Where it is possible to treat a service user safely and lawfully without detaining them under the Mental Health Act, the person should not be detained. Independence should be encouraged with a focus on promoting recovery.

2

Empowerment and involvement: Service users should be fully involved in care, support and treatment decisions. If appropriate, the views of families, carers and others should be fully considered.

3

Respect and dignity: Service users, their families and carers should be treated with respect and dignity and listened to by professionals.

4

Purpose and effectiveness: Decisions about care and treatment should be appropriate to the service user with clear aims that promote recovery, and following best practice guidelines.

5

Efficiency and equity: Relevant organisations should work together to ensure mental healthcare services are of a high quality and support safe, timely and supportive discharge.



What is Mental Capacity?

Every individual should be presumed to have the capacity to make their own decisions. A decision can only be made for someone else if all practical steps have been taken without success.

The Mental Capacity Act says that a person is unable to make their own decision if they cannot do one or more of the following four things:

- > Understand information given to them
- > Retain that information long enough to be able to make the decision
- > Weigh up the information available to make the decision

Making decisions for someone

If, having taken all practical steps to help someone, it is agreed that a decision should be made for them, that decision must be made in the service user best interests. **The Mental Capacity Act sets out a checklist of things to consider** when deciding what is in the service user best interests. This decision would be made by the most appropriate professional who should, where appropriate, take the views of the carer into account.

Power of Attorney

A Power of Attorney is a legal document that allows the named person (such as a carer) to deal with the affairs (usually financial) of the person who has chosen them as their attorney. The most common type of Power of Attorney is a Lasting Power of Attorney (LPA), which is drawn up while the person still has the mental capacity to give permission for the person or people to deal with their affairs after they lose mental capacity.



There are two types of LPA:

1	Property and financial affairs	Gives the attorney the authority to make decisions about the person's financial affairs.
2	Health and welfare	Gives the attorney the authority to make decisions about the person's personal welfare and healthcare.

All Power of Attorney documents can be obtained from the Office of the Public Guardian and have notes to aid completion or you can enlist the services of a solicitor. More details can be accessed from them at <http://www.justice.gov.uk/about/opg> or by calling **0300 456 0300**

Deputyship - If the person you care for has lost the capacity to manage their finances and an LPA is not in place you can apply to the Court of Protection to be appointed as a Deputy. This is similar to LPA but the Court of Protection oversee the process much more rigorously as it is they, and not the individual who has appointed the Deputy.

Advanced Statements and Advanced Directives

Individuals can record their wishes about care and treatment in advance, so these can be understood if they become unwell. **This can be done in two main ways:**

- > Advance Decisions to Refuse Treatment (ADRT) are legally binding decisions to refuse specific medical treatments
- > Advance Statements – documents that set out a person's general wishes and preferences, such as care for dependants or spiritual needs

Both should be taken into account when planning care.

The law is changing, and over time these will be brought together into Advance Choice Documents (ACDs). This is intended to provide a clearer and more consistent way for people to record their wishes.

For now, the current legal framework remains in place. If the person you care for has recorded their wishes, it is important that the clinical team is aware of them, as they should be considered when planning treatment and making “best interests” decisions.

Advance Statement

An advance statement is a general preference about the service user treatment and care. It is not legally binding, but medical professionals should still make a practical effort to follow the service user wishes. The Mental Capacity Act states that decisions about your care and treatment should be made in the service user 'best interests'. The advance statement should reflect the service user views, beliefs and values. The information will be useful when people make decisions that affect the service user. **An advance statement is also known as a 'statement of wishes.'**

Advance Decisions To Refuse Treatment (ADRT)

An advance decision is legally binding. It gives the service user the legal right to refuse specific medical treatment in future when they may not have the mental capacity to make the decision for themselves at the time. **An advanced decision can not be used for anything else.** Certain treatment can only be refused if the ADRT is in writing, signed and witnessed.

Anyone wanting to make an ADRT is advised to seek legal advice.

Advanced care plans

When an individual is well, they may wish to make an advanced care plan to direct their treatment if they become unwell in the future. **An advanced care plan is written by the individual with the support of a staff member if requested.** It should take into account the individual's wishes; however, it is **not a legally-binding document** and therefore does not guarantee that all their wishes will be fulfilled.

This could include treatment preferences, such as:

- > Things that have worked well and things that have not worked so well
- > Domestic arrangements, including care of pets
- > Finances
- > Childcare
- > Dietary requirements
- > Consent e.g. sharing of information in medical records

It can be really useful for you to be involved in writing the advanced care plan and have a copy or know how to access it when required.

Types of Advocacy

All people are very different from each other. Their needs for support are different and may change during their life. **A variety of advocacy has developed to recognise these differences:**

- > Case advocacy
- > Self advocacy
- > Peer advocacy
- > Paid independent advocacy
- > Citizen advocacy
- > Statutory advocacy (IMHA, IMCA, IMCA DoLS)
- > Patient advocacy
- > Carer advocacy:

Carers can also access independent advocacy in their own right. This is separate from patient advocacy and is there to support you to understand information, express your views and feel confident in your involvement in care where appropriate.

Email: carers@katemercer-training.com

All advocacy types are of equal value. What advocacy is used, and when, should depend on what is best suited to the service user who seeks it.

Complaints

Informal complaints – concerns

There are times when people using our services are unhappy about minor aspects of their care or their environment. We find that the best way to sort things out quickly is to talk to the people who are providing the care, this could be; a support worker, nurse, doctor or service manager. We encourage our staff to work with individuals to find a speedy resolution.

Formal Complaints

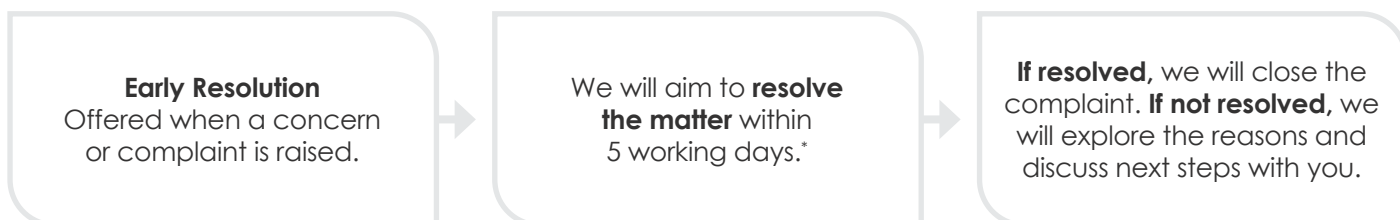
These are complaints that we have not been able to resolve informally, they can be verbal or in writing. We have a **three stage process for dealing with formal complaints**:

- > Stage 1: Service Manager – Internal Review
- > Stage 2: Operations Director – External Review
- > Stage 3: Director of Nursing

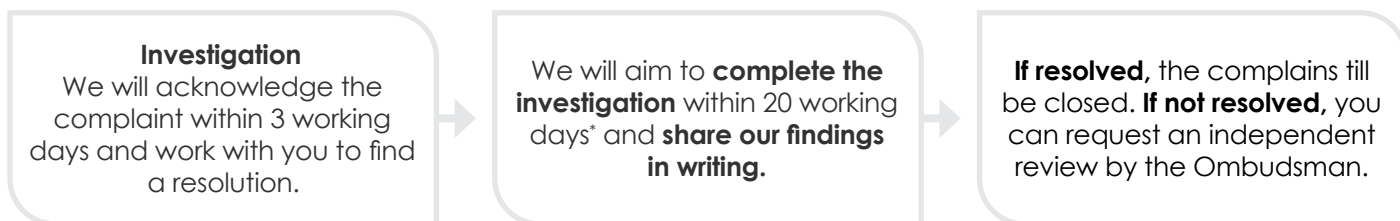
Complaints can also be sent to us online by using <https://www.cygnetgroup.com/contact/>
Be sure to mention which service you want to make a complaint about.

Cygnet's complaints process for our English and Welsh services:

Stage 1 process:



Stage 2 process:



* While we aim to resolve concerns quickly, some matters may take longer. Early Resolution may take up to 10 working days and investigation may take up to 60 working days if the issue is complex. If more time is needed, we'll keep you informed and let you know when to expect a response.

Cygnnet Carer Networks

Do you have ideas about what would make Cygnnet even better? Cygnnet believes that service users, residents and carers can be influential partners in supporting change and improvements across our services by giving helpful feedback. We are looking for individuals with a lived experience of our services to join Cygnnet's Carers Network and help influence and shape the design and improvement of our health and social care services.

In the voluntary role of a Service User or Carer Representative, you will be supported by Cygnnet staff as equal partners in the development of local services and policies.

For further information, please email Family, Friends and Carers on:



Family&Friends@cygnnethealth.co.uk

Jargon Buster

You may see some of the following names for things involved with the service of the person you care for. **Here are some explanations of what these mean** which we hope you will find useful. If you're not sure about something, or want to find out more, please just ask someone at the service the person you care for uses.

Assessment - a thorough look at the needs of the person you care for. This will look at the person's mental health needs, but will also consider the impact of their mental health upon their physical health; their ability to get involved in their daily self-care; their social situation; work and learning; and other areas.

Care Act - this is a piece of law from 2014, which entitles everyone who may have social care needs to an assessment from the local authority. This may be done by a mental health service, depending on the situation.

Care coordinator - a person who works for a mental health team, usually a nurse, occupational therapist or social worker, who supports a service user to create a care plan. They then make connections with the people and services identified in the care plan to support the person to recover from their current difficulties.

Care plan - a document that is created for the service user following meeting with their treating professionals. This will be proportionate, depending on the person's needs. Carers should be invited to contribute when the service user consents, as well as receiving a copy.

'Carer Aware' - this is when services and organisations are mindful of the support and pressures upon carers, and involve them in shaping service provisions.

CPA - this stands for the 'Care Programme Approach', a multidisciplinary care and support planning process for people with complex mental health issues. Someone receiving a service under CPA will be offered a care and support CPA plan.

CTR - this stands for 'Care and Treatment Reviews. CTRs are part of NHS England's commitment to transforming services for people with learning disabilities, autism or both.

Crisis plan - this is a plan created with the service user, carers and different team members, giving options for the person and their carer should the experience a mental health crisis.

Experts by experience - these are people who have a lived experience of mental distress, and who may have used mental health services. Their insight into how services work, and their suggestions for improving them, are very useful.

Recovery - this is the idea in contemporary mental health services that people can define for themselves how they will recover from their mental distress, and what this will look like when it has happened. For some people with enduring mental health conditions, this might mean having no medical symptoms of mental disorder, but rather being able to manage these and participate in daily life as the person wishes.

Safeguarding - this means everyone has the rights to feel safe at home. Safeguarding is a way of protecting people and is the responsibility of all health and social care professionals under the Care Act 2014.

For more information on Jargon – please see Think Local Act Personal website
<https://www.thinklo-calactpersonal.org.uk/Browse/Informationandadvice/CareandSupportJargonBuster/>

Mental Health Conditions

Understanding a diagnosis Caring for someone who has a mental health problem or learning disability – particularly for new carers – can be daunting and confusing if you are not familiar with how it may affect the person you care for. There are many different types of mental health conditions and illnesses. You can find out more about some of them here:

More information on some of the more common mental health problems our patients are diagnosed with can be found online

<https://www.cygnetgroup.com/service-users-carers/useful-information-helpful-resources/mental-health-conditions/> or <https://www.nhs.uk/mental-health/conditions/>

Information on Medication

Many people with mental health difficulties need to take medication, either on a short or long-term basis. While medication is not a cure, it can treat symptoms, helping individuals to cope better and benefit from other therapies and sources of support. A wide range of medicines are used to treat individuals with mental health problems. If you would like more information about a type of medication you can find it from:

<https://www.cygnetgroup.com/service-users-carers/useful-information-helpful-resources/medications/> or <https://www.nhs.uk/conditions/medicines-information/>



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Integrity

Trust

Empower

Respect

Care