Elysium Healthcare

Family, Friends and Carers

Introduction

Carers* play an essential role in the overall care provided by our staff to the people we support. They are the constant and consistent voice for those we care for throughout their journey with Elysium, from pre-admission assessments, during the admission, and are a vital part of any discharge planning. Carers can promote the rights of their loved ones and advocate on their behalf, supporting staff to better understand their wants, views and wishes. Carers can help loved ones navigate the complexities of a hospital admission or residential placement and can help in practical terms by supporting with benefits, and just by being there, they are a familiar face.

When service users* are placed a long way from home and family networks, having carers being able to visit and communicate on a regular basis can provide a welcome link to home, and a vital support in recovery.

Carers can also influence care being delivered by providing feedback on services, making suggestions for improvements, and helping to raise awareness of issues when things are not going well.

Carers may often not recognise the role they play in shaping services, but it is important that Elysium recognise the valuable contribution they make in supporting their loved one's recovery, and that they are considered very much a part of the team.

James Holloway – *Elysium Healthcare Group Head of Safeguarding and Carers Lead*

*Throughout this guide we will refer to service users, residents and clients (or anyone we provide services for) as service users and family, carers, and friends as simply carers.

Who is a ‘Carer’?

As defined by NHS England, a carer is:

> *“anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.”*

When we refer to carers in this document, this is inclusive of both adult and young carers. We use the term ‘carer’ in its broadest sense to include the most significant people in the life of those we support, including spouses, parents, family members, friends, and young carers. The carer is not always the nearest relative.

It is important to acknowledge that some carers may not think of themselves as carers. It can also be difficult for carers to see their caring role as separate from the relationship they have with the person for whom they care.

This booklet aims to recognise the needs of carers and provide useful and important information to help them throughout their loved one’s journey. In addition, the objective is to empower carers to be involved in the provision of care and service development.

Our commitment

Carer's Charter

Principle One: Acknowledging your voice

We will recognise your expertise, knowledge, and the important role that you play in your loved one's care and treatment, and:

- Listen to you without bias or prejudice and take your worries and concerns seriously
- We will communicate clearly with you and keep the language jargon free
- Recognise that you have relevant and important information about the person you care for
- Value and respect your opinion and where necessary keep it confidential
- Take your views into account when decisions are being made about the person you care for
- Share information with you about the person you care for wherever this is helpful and possible

Principle Two: Involvement in care

We will welcome your involvement in care and:

- Recognise that you are integral to the whole care plan, initial assessment, risk assessment, reviews, and discharge. Involve you in planning the care and discharge for your relative or friend
- Give you a copy of any care plan for the person for whom you care, with their agreement
- Provide you with information about the way our service works
- Signpost you to relevant information and advice to enable you to get help from carer support networks

Principle Three: Training our staff

We will train our staff to be aware of carers' needs and:

- Ensure all our staff can identify carers and recognise their role as partners within the service user's care and treatment
- Involve our staff in developing information, support and other services for carers
- Involve carers in training our staff about customer care

Principle Four: Developing our services

We will value your involvement in the development of our services, and:

- Give you the opportunity to state your views on the quality of our services
- Give you the opportunity to be actively involved in planning, development and evaluation of services through the carers representatives attending clinical governance
- Inform you of service developments and give you adequate notice of meetings, consultation periods and other relevant events
- Properly reimburse all carer volunteers who help in service planning and training

Think Family

Think Family is an approach which aims to promote the importance of a family focus when overcoming multiple or complex problems. At Elysium Healthcare, we recognise that it is the responsibility of all staff to consider the needs of the whole family and be responsive to their needs.

For more information on Think Family, visit www.scie.org.uk/publications/guides/guide30/

Triangle of care

The Triangle of Care emphasises the need for better local strategic involvement of carers and families in the care planning and treatment of people with mental ill-health. We are committed to the six key standards to achieve better collaboration and partnership with carers:

1. Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
2. Staff are 'carer aware' and trained in carer engagement strategies.
3. Policy and practice protocols regarding confidentiality and sharing information, are in place.
4. Defined post(s) responsible for carers are in place.
5. A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
6. A range of carer support services is available.

For more information on the Triangle of Care, visit carers.org/resources/all-resources/53-the-triangle-of-care-carers-included-a-guide-to-best-practice-in-mental-health-care-in-england

My involvement

What should I expect when my loved one arrives at the service?

As a carer, you can expect support and involvement from the point your loved one arrives at the service:

1. Staff are welcoming in their interactions with you.
2. Clear information is provided on the service, your loved one's care and your involvement as a family member, friend or carer.
3. You are given a named contact at the earliest opportunity and are offered a face to face induction meeting (or telephone meeting if this is more suitable for you) close to the point of admission, plus ongoing contact thereafter. This should include provision of key information that helps you familiarise yourself with the unit, cope with stresses you may experience at this time, and tells you what to expect.
4. Be signposted to alternative forms of support, for your own practical and emotional need for example independent carers' advocacy services.
5. Be provided a clear confidentiality and information sharing protocol which is positive and proactive and seeks to engage and involve you wherever possible.

Confidentiality and information sharing

Sharing information with carers

Carers provide important information that can help us have a better understanding of the needs of the service user. Therefore it is important we communicate well and work in partnership with carers and the service user. This is known as the triangle of care, ensuring effective care and better clinical outcomes.

Consent to share information

Sometimes there can be difficulties in relation to confidentiality and sharing information. When a service user wants to keep personal information private to themselves, then these wishes must be respected by staff. Staff members will:

- Discuss with the service user what particular information they wish to keep private
- Explain to the service user the importance and value of sharing information with those who care for them
- Explain to you at an early stage what information can be shared, and if information cannot be shared explain the reasons for this
- Answer any queries you make have on this topic
- Ensure that you receive as much information as possible to help you in your caring role

Issues around confidentiality should not be used as a reason for not listening to you or for not discussing fully with the service user the need for you to receive information so that you can continue to support them.

Types of information

The ability to share information varies depending on the circumstances. Staff should check with you what information you already know, such as diagnosis and treatments, as any information you are already aware of is not to be treated as confidential. Providing you with general information about an illness or offering emotional and practical support does not breach confidentiality.

There are three different types of information:

- **General information** includes literature already in the public domain such as leaflets, published materials and websites. The content may include information on physical and mental health conditions, medication and their side effects, relevant legislation, including the Mental Health Act, rights for service users and rights for carers, discharge information if this directly impacts the carer, information for local and national services, consent and confidentiality restrictions requested by the service user and how to access help and support
- **Personal information** relates to specific information about the person you are caring for, for example the diagnosis, medication and its effects, the care plan, discharge care planning and contingency planning
- **Sensitive personal information** includes information of a highly personal nature, details of previous sexual or emotional abuse, sexual activity, breaches of the law and the service users views about family members

When can confidentiality be broken?

Any decision to break confidentiality must always be made in the best interest of the service user and 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'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 service user'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.

Checklist: Information sharing

Factual information

Carers are given general factual information, both verbal and written about:

- ☐ A diagnosis
- ☐ What symptoms/behaviour may occur in people with this diagnosis, and how to support the person
- ☐ Medication – benefits and possible side effects
- ☐ Local health services available
- ☐ What different care and treatment might be used for people with this diagnosis or health issue
- ☐ Local and national support groups

Help and guidance

Carers are helped to understand (subject to the service user agreeing):

- ☐ The present situation
- ☐ Any confidentiality restrictions requested by the service user
- ☐ The service user's treatment plan and its aims
- ☐ Any written care plan, emergency care/crisis plan or recovery programme
- ☐ The role of each professional involved in the service user's care
- ☐ How to access help, including out-of-hours services

Additional Support

Carers are given:

- ☐ The opportunity to see a professional on their own
- ☐ The right to their own confidentiality when talking to a professional
- ☐ Encouragement to feel a valued member of the care team
- ☐ Confidence to voice their views and any concerns they may have
- ☐ Emotional and practical support
- ☐ Assessment of their own needs with their own written care/support plan

FAQ

Why is my family member being cared for in a hospital or a care setting?

If your family member has been admitted to one of our hospitals, this is so they can receive the treatment and care needed to improve their health or to manage their condition. If your family member has come in to one of our care or residential settings it could be that they are getting ready for more independent living or that they cannot live at home without some more support. Both the hospital and residential teams will work in partnership with your family member and, with consent, you. This is to make sure that their care and support needs are met, and future plans are in place for them.

Everyone is an individual with individual needs. Each person will have identified, informed, and agreed treatment goals and aspirations so it can be difficult to say just how long their stay will be. Our joint aim is to ensure that their stay is for the shortest time possible to enable them to continue their care pathway in a positive and supportive way.

We recognise that some individuals in our care will live with us longer term in the service which is their home. We will continue to work with your loved one to ensure that they live their lives meeting their personal life goals in order to fulfil their hopes and dreams.

Who will look after my family member?

In our care or residential settings, service users have access to both clinical, therapeutic and support staff. They will be looked after by this team of caring professionals who will all work towards helping them meet their goals. Within a hospital setting the treatment team, also known as a Multidisciplinary Team (MDT) may be made up of:

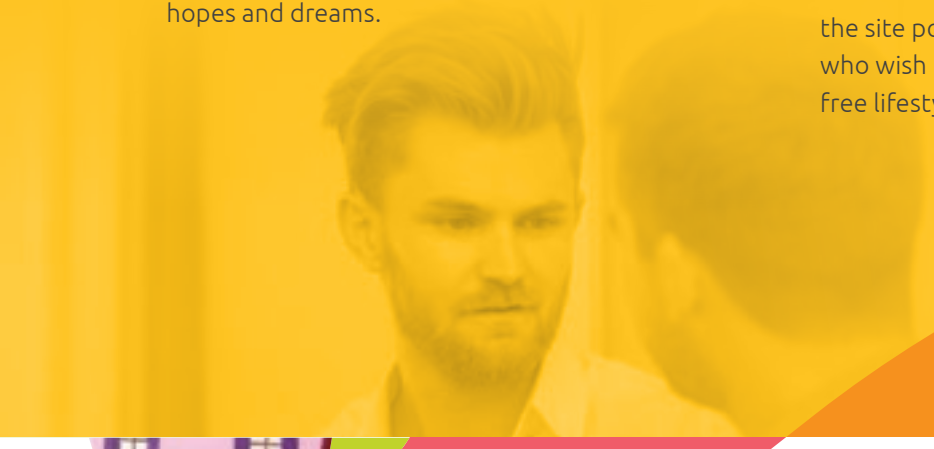
- Responsible Clinician or Doctor
- Nurses and Healthcare Assistants
- Psychologist
- Social Worker
- Occupational Therapist
- Individual Therapist

Where will my family member sleep?

Most services offer ensuite bedrooms which, if appropriate, can be personalised so your family member can feel at home. Where accommodation is shared, which is sometimes the preference of those in our care, this will be an informed choice and be reviewed whenever your family member requests.

Is smoking allowed at Elysium services?

The majority of our services are smoke free sites, and each service will inform your family member of the site policy. We are happy to support individuals who wish to stop smoking and maintain a smoke free lifestyle.



What support is available to me?

We recognise that the role of a carer can be very demanding, difficult, and isolating. The following information provides guidance on how to access support that you may need.

Your GP

It is important that you let you General Practitioner (GP) know that you have caring responsibilities. They will be able to advise you how to reach the appropriate support to meet your needs.

Carer's assessment

Anyone who provides unpaid regular and substantial care is entitled to have a carers' assessment. This is an assessment of your own wellbeing and how caring has affected you.

You are entitled to an assessment of your needs as a carer, even when the person you support refuses to use the services they need.

An assessment should happen at least once a year, and when there are any major changes to your circumstances or those of the person you care for.

After the assessment, you should receive a written support plan setting out how any identified needs will be met. Local services may vary.

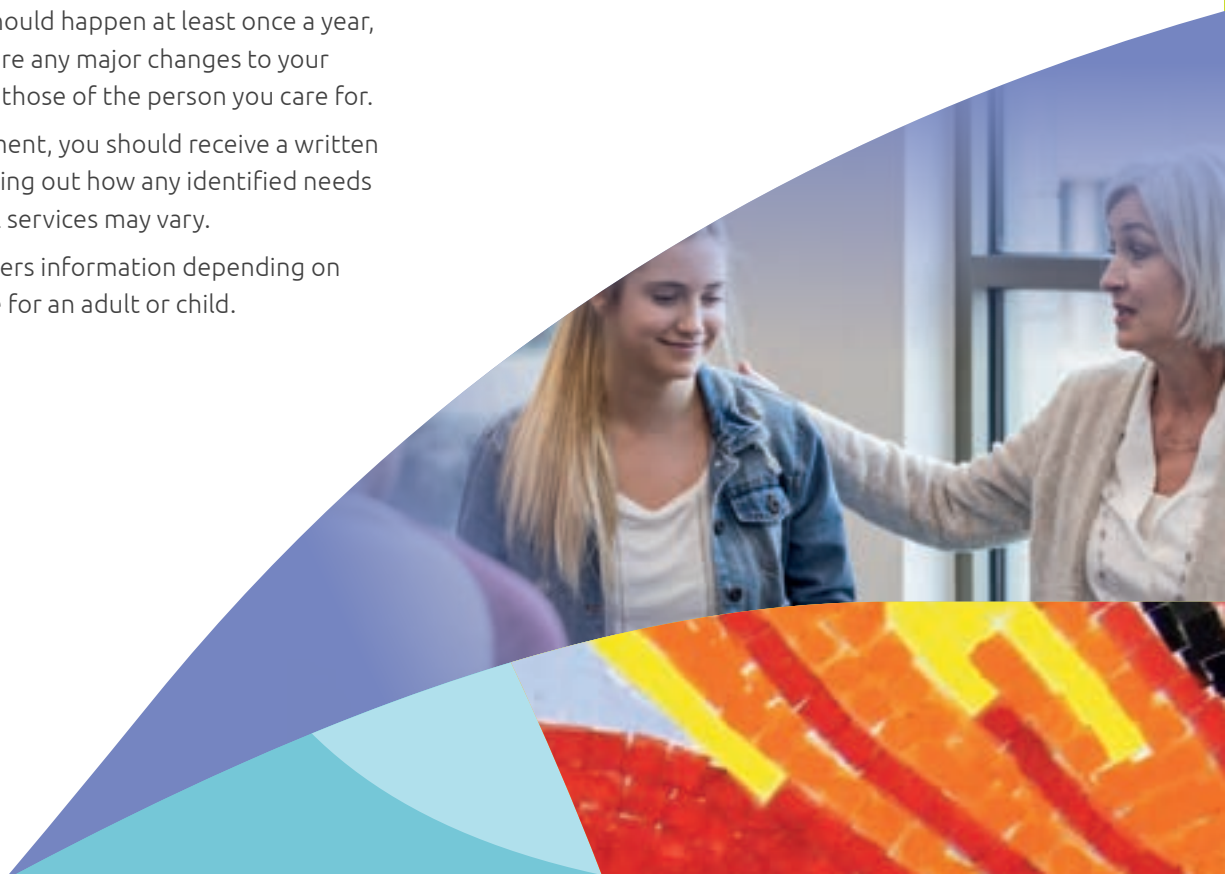
The following offers information depending on whether you care for an adult or child.

For adult services:

Local councils can provide care and support for carers. A carer's assessment is for carers over 18 years old who are looking after another adult over 18 years old who is disabled, ill or elderly. It is an opportunity to record the impact caring has on your life and what support or services you need. The assessment will look at your physical, mental, and emotional needs, and whether you are able or willing to carry on caring.

You will be entitled to an assessment regardless of the amount or type of care you provide, your financial means or your level of need for support. You don't necessarily have to live with the person you are looking after or be caring full-time to have an assessment. You may be juggling work and care and this is having a big impact on your life.

For further information about carer assessments, visit: www.carersuk.org/help-and-advice/practical-support/getting-care-and-support



For child and adolescent services:

Local councils are required to assess parent carers on the appearance of need or where an assessment is requested by the parent. This is called a parent carer needs assessment.

The local council must be satisfied that the child and their family come within the scope of the Children's Act, i.e., that the child is a child in need.

The local council must then assess:

- whether a parent carer has needs for support and what those needs are
- whether it is appropriate for the parent to provide, or continue to provide, care for the disabled child, in the light of the parent's needs for support, other needs and wishes

Parent carers' needs assessment must also consider:

- the wellbeing of the parent carer
- the need to safeguard and promote the welfare of the child cared for, and any other child for whom the parent carer has parental responsibility

For further information about parent carer assessments, visit: www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/young-carers-and-carers-of-children-under-18

Carer advocacy

There are groups which may be able to act as an advocate for you, or the person you care for, when you make a complaint.

Advocacy is when someone makes sure that your opinion and experiences are properly heard by health or social services. They can also contact organisations on your behalf if you are not comfortable doing this and will make sure that none of the things you want to say get forgotten, missed or ignored.

Contact your local carer service and ask if advocacy is something they can support you with. Or they may be able to put you in touch with other local organisations that provide advocacy.

Carers UK has a self-advocacy guide for carers which provides information and suggests ways to help carers advocate for themselves: www.carersuk.org/search/self-advocacy-eng

Personal budgets for carers

Personal budgets for carers are available where services that have been identified through the carers' assessment process can be bought by the carer. Personal budgets can give people greater control and flexibility in the support they receive. For more information visit: www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/

Useful links (carer support)

Carers UK has a telephone helpline available on **0808 808 7777** from Monday to Friday, 9am – 6pm or you can contact them by email (advice@carersuk.org). For more information, visit www.carersuk.org/help-and-advice/talk-to-us. They have also put together a simple tool for people who are new to caring www.carersuk.org/upfront/

For details of local carers' organisations, visit www.carersuk.org/help-and-advice/get-support/local-support

Support from other carers is available from Carers UK via an online forum www.carersuk.org/help-and-advice/get-support/carersuk-forum

Citizens Advice provides free, independent, confidential and impartial advice in England, Wales, Scotland & Northern Ireland www.citizensadvice.org.uk

Contact is a national charity that supports the families of children with additional needs in England, Wales, Scotland & Northern Ireland www.contact.org.uk
Call **0808 808 3555** or email helpline@contact.org.uk

Mental Health

NHS England has produced a secure carer toolkit which sets out how carers of people who use secure mental health services should be engaged, supported, and empowered. To access the toolkit visit: www.England.nhs.uk/securecarerstoolkit

The Mental Health Foundation have produced an excellent A-Z of everything mental health which you can access here: www.mentalhealth.org.uk/a-to-z

Mind provide advice and support to empower anyone experiencing a mental health problem. They campaign to improve services, raise awareness, and promote understanding. www.mind.org.uk

The aim of Rethink is to improve the lives of people severely affected by mental illness through local groups and services, expert information, and successful campaigning. www.rethink.org

Carers Trust is a major charity for, with and about carers. They work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems: www.carers.org

Learning Disabilities and Autism

NHS England have produced resources about involving people with a learning disability, autistic people and family carers: www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/

The National Autistic Society offers impartial, confidential information along with advice and support for people on the autism spectrum and their families and carers. www.autism.org.uk

Neurological

Headway is the UK-wide charity that works to improve life after brain injury by providing vital support and information services: www.headway.org.uk

The Stroke Association offers resources to families and survivors of stroke: www.stroke.org.uk/peer-support

The Encephalitis Society improves the quality of life of all people affected directly and indirectly by encephalitis by providing support and information and raising awareness: www.encephalitis.info

The Huntington's Disease Association helps people living with Huntington's disease to live a better life. They work to improve care and support services for people with Huntington's disease, educate families and professionals, and champion people's rights: www.hda.org.uk

The Multiple Sclerosis Society (MS) offer information on support groups and ways to connect with people who understand what life's like with MS: www.mssociety.org.uk

The Motor Neurone Disease Association funds and promotes global research in to Motor Neurone Disease (MND) and provides support to people in England, Wales and Northern Ireland: www.mndassociation.org

Children and Education

If you're worried about a child or need advice and support for coping with anything affecting your child's emotional or mental health, there are different ways to seek help.

www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/camhs-information-for-parents-and-carers/

The **NSPCC** is a charity who work to protect children and prevent abuse: www.nspcc.org.uk

How can I learn more about my loved one's condition and the care they are receiving?

Legal

How are carers protected under the law?

The Carers Trust offers information on how carers are protected by the law. The legislation relates to the following:

- Equality Act 2010
- Care Act 2014
- Children and Families Act 2014
- Your human rights
- Social Services and Well-being (Wales) Act 2014

Mental Health Act

The Mental Health Act 1983 (amended 2007) is a piece of legislation (in England and Wales) which informs people with mental health problems who are detained under the Mental Health Act, what their rights are regarding:

- Assessment and treatment in hospital
- Treatment in the community
- Pathways into hospital, which can be civil or criminal

Some service users go into hospital voluntarily and are known as informal service users. Some service users go to hospital without their consent because of the severity of their mental illness. This is known as being a formal service user. Formal service users are detained under the Mental Health Act 1983 (amended 2007).

Mind have a really helpful website which tells you all about the Mental Health Act and this can be found here: www.mind.org.uk

Mental Capacity Act

The Mental Capacity Act 2005 is a piece of legislation (in England and Wales) for people who cannot make decisions for themselves because they do not have the mental capacity to make them. It tells them:

- What they can do to plan ahead
- How they can ask someone else to make decisions for them
- Who can make decisions for them if they haven't planned ahead

The Mental Capacity Act is important for people who think that their ability to make certain decisions will be affected in the future because of their mental health problem, an illness, an injury, or outside reasons like the effect of prescribed medication.

Mind have a really helpful website which tells you all about the Mental Capacity Act and this can be found here: www.mind.org.uk

Safeguarding

Safeguarding is protecting an individual's right to live in safety, free from abuse and neglect. It is about people and organisations working together to prevent and stop both the risks and experience of abuse or neglect, while at the same time making sure that the individual's wellbeing is promoted.

Elysium Healthcare is committed to safeguarding and promoting the welfare of all individuals within our services. Elysium Healthcare has a duty of care to protect all individuals using our services and to ensure that all employees treat people for whom care is provided with dignity and respect. Working in partnership with other agencies, we are dedicated to reducing risks of abuse and learning from incidents.

Information about conditions

Mental Health Conditions

The Royal College of Psychiatrists offers information written by doctors in collaboration with service users and carers. Find out more here:

- **Problems and disorders** www.rcpsych.ac.uk/mental-health/problems-disorders
- **Support, care and treatment** www.rcpsych.ac.uk/mental-health/treatments-and-wellbeing
- **Young people's mental health** www.rcpsych.ac.uk/mental-health/parents-and-young-people

Neurological Conditions

There are several organisations which offer information on neurological conditions:

- **Brain injury** www.headway.org.uk/about-brain-injury/
- **Stroke** www.headway.org.uk/about-brain-injury/individuals/types-of-brain-injury/
- **Encephalitis** www.headway.org.uk/about-brain-injury/individuals/types-of-brain-injury/encephalitis/
- **Huntington's disease** www.hda.org.uk/huntingtons-disease/what-is-huntingtons-disease
- **Multiple Sclerosis** www.mssociety.org.uk/about-ms/what-is-ms
- **Motor Neurone Disease** www.mndassociation.org/about-mnd/what-is-mnd/

Learning Disabilities and Autism

Information is available on learning disabilities and associated conditions:

- **Learning disability** www.mencap.org.uk/learning-disability-explained
- **Autism** www.mencap.org.uk/learning-disability-explained/conditions-linked-learning-disability/autism-and-aspergers-syndrome
- **Down's syndrome** www.mencap.org.uk/learning-disability-explained/conditions-linked-learning-disability/downs-syndrome

Information about medication

Medication

Medication can be an important part of treatment. To find out more about the commonly used medication associated with mental health problems, including side effects, the charity Mind have an informative page on their website: https://www.mind.org.uk/information-support/drugs-and-treatments/medication/about-medication/

Easy Read and Audible Guides to Medication

The University of Birmingham has produced some great Easy Read and Audible medication guides.

birmingham.ac.uk/research/activity/ld-medication-guide/downloads/medicine-information.aspx

Regulation

Hospitals and Care Homes are regulated in England by the Care Quality Commission (CQC), hospitals in Wales are regulated by the Healthcare Inspectorate Wales (HIW) and Care Homes in Wales are regulated by the Care Inspectorate Wales (CIW). These are independent groups who visit and inspect services to make sure that they are meeting set standards. Following a visit, they produce a report which highlights what is working well and what services need to do to improve. This helpful process ensures that the quality of care improves all the time. The regulators will also talk with the people we support to hear their views on the care they receive.

The independent regulator of health and social care in England: www.cqc.org.uk

The independent regulator of healthcare in Wales: www.hiw.org.uk

The independent regulator of social care in Wales: www.careinspectorate.wales

NHS England: www.england.nhs.uk

How can I support the service to make improvements?

Complaints, compliments, and suggestions

How do I make a complaint?

Your family member or loved one and you are important to us, and we want them and you to feel safe and be comfortable to raise any concerns you each may have. Every service has a complaints procedure which will be made available to you and your family member when they arrive at one of our services. However, if you do not feel comfortable raising your concerns directly with the service you can contact FamilyandCarerenquiries@elysiumhealthcare.co.uk

You may also choose to take up the issue with the relevant regulator:

- CQC is the independent regulator of health and social care in England: www.cqc.org.uk
- HIW is the independent regulator of healthcare in Wales: www.hiw.org.uk
- CIW is the independent regulator of social care in Wales: www.careinspectorate.wales

How do I share something positive?

It is always good to hear when we are doing things well. Feel free to write or tell staff or the Manager of the service what has pleased you. You can also email any feedback to us at: FamilyandCarerenquiries@elysiumhealthcare.co.uk

More information about how to make a complaint or compliment can be found on our pdf, downloadable here:

English: www.elysiumhealthcare.co.uk/wp-content/uploads/2020/09/Web-How-you-can-raise-a-concern_-make-a-complaint_-or-leave-a-compliment.pdf

Welsh: www.elysiumhealthcare.co.uk/wp-content/uploads/2020/09/Concern_Complaints_Compliments-Welsh-WEB.pdf

How do I make a suggestion?

If you have any suggestions on how we can improve the service we provide or our engagement with carers, please email us at: FamilyandCarerenquiries@elysiumhealthcare.co.uk

Carer forums and service development opportunities

From time to time, we may ask carers to support service development, improvement and coproduction initiatives. This could include:

1. Advising on Elysium policies
2. Taking part in local activities for service users and carers.
3. Attending service users or carer events and workshops.
4. Helping develop or review information leaflets.
5. Joining a committee or group to support practice developments.
6. Supporting training development and delivery.

If this is something you would be interested in supporting, please speak to a staff member at your service to find out about any local opportunities.
Or email: FamilyandCarerenquiries@elysiumhealthcare.co.uk

Local information

Each Elysium site will also have their own local information pack covering site-specific information:

- About the service
- Key terms and definitions
- Local contact information
- Support available
- Carer engagement opportunities e.g. carers' forum or events
- Visiting the service
- Staying in contact by telephone and videoconferencing
- Site-specific policies e.g. smoking
- Local carers' groups and resources
- Other important information

Accessibility

We provide information in other languages, Braille or British Sign Language (BSL) on request. If you are a Deaf family member or carer you can contact Elysium Healthcare using a BSL interpreter from the SignVideo link on our website.

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