



Cumbria, Northumberland,
Tyne and Wear
NHS Foundation Trust



My ongoing rehabilitation journey

A self-management guide for
Northumberland Head Injuries Service

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If you would like this guide to be sent to you via email please contact
Tel: 01670 394 150 or email: nhisadmin@cntw.nhs.uk

Please do not use these contact details for any other enquiries.

Foreword

This booklet provides useful guidance, practical advice and helpful strategies that will help in your rehabilitation and life after being discharged from Northumberland Head Injuries Service.

Self-management is part of your rehabilitation journey. You will be will be supported by your head injury team to develop the skills to manage your own condition, moving towards increased independence and wellbeing.

Some of the strategies mentioned in this booklet I still use 17 years after leaving hospital. They are an important part of my everyday life. They have helped me cope with moving on in the world and helped me manage my difficulties after discharge.

I acquired a brain injury in 2003. After neurosurgery and a stay in the General Hospital I went to Hunters Moor neuro-rehab hospital (which later became Walkergate Park). Initially I required physiotherapy, speech therapy, occupational therapy and clinical psychology.

- In physiotherapy, I was shown how to do certain physical exercises, and given a small guide.
- In occupational therapy, I learned practical living strategies for coping with managing tasks both in the house and outdoor life.
- Clinical psychology demonstrated and practiced with me, how to use technology to help find a way around my cognitive problems.

During my rehabilitation, therapies did effectively help me to practice self management. Staff were caring, helpful and fully supportive. I continue to use strategies from all of my former therapies, except for Speech Therapy. After speech therapy, all that was required was practice: to talk more. This is something others may be less happy about than I was!

This booklet is an excellent easy to read, practical guide to Self Management.

Nicholas Hedley, Chairman of the Service User Forum

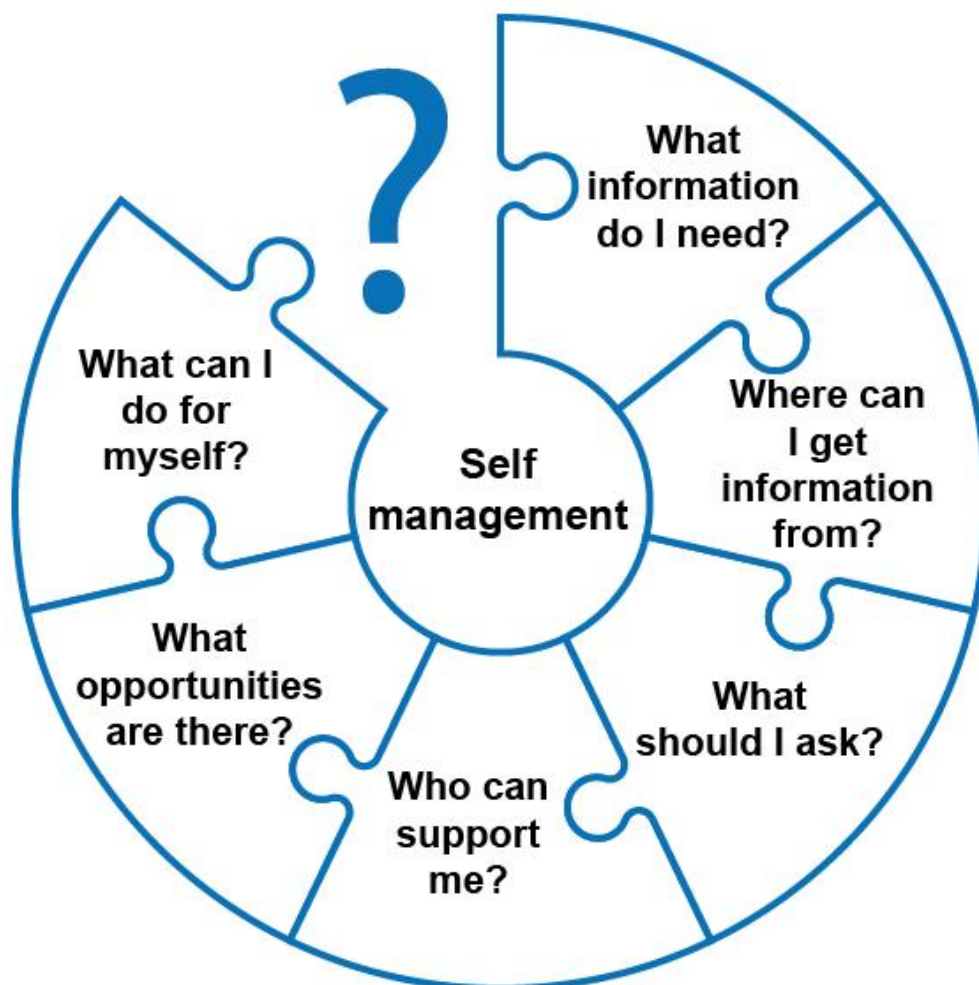
My ongoing rehabilitation: what is self-management?

What is self-management?

Following your discharge from Northumberland Head Injuries Service, it is an essential part of your rehabilitation journey to self-manage your neurological condition, but what does this mean?

It means giving you the skills, knowledge and information that you need to help you make informed choices and decisions in your life, to manage your condition better. This aims to improve your overall health, wellbeing and quality of life.

This pack is designed to guide you to where you can find some of that relevant support, guidance, knowledge and skills. With the help from your friends, family, carers and professionals around you, we encourage you to take as many opportunities as possible, to get the most out of your rehabilitation journey.



My difficulties and goals

My difficulties

A good start is to identify areas you may have some difficulties with during the day. This can be done with the help from others. Examples may be, difficulties remembering things, difficulties using your hand to hold things or difficulties with fatigue. See if you can make a note of them below.

My goals

It is also important to have ongoing goals no matter how big or small they may be. This will help direct you to the type of support, groups or websites you might find useful.

The goals will be ones you decided on once you were finished with formal rehabilitation from NHS services. These are goals that you set for yourself.

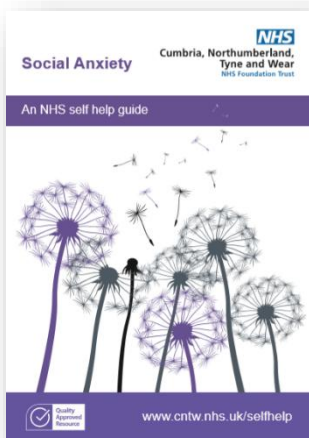
For example, to complete my exercises once a day, to attend a weekly peer support group, to ensure I have a rest on the bed each afternoon to help manage my fatigue. With help from others, have a go at writing down what you'd like to be able to achieve.

Managing my mental health and wellbeing

Following your discharge from formal services you may feel a range of emotions. We hope that you feel positive about taking the next step forwards in your rehabilitation journey, however you may also feel worried or anxious or maybe low in mood.

Everyone reacts differently to events and changes, in the way that we think, feel and behave. It's important that you take care of your mind as well as your body and to get further support if you need it.

Top Tip: Have a look at the 'Condition specific support' on page 17 as a lot of this advice can be applied at any time.



Self Help Guides

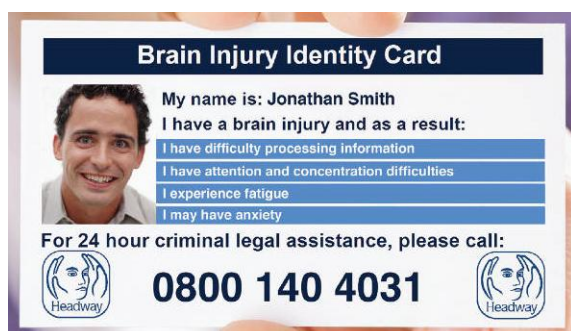
Our Trust provides 23 self help guides that can be downloaded or listened to at www.cntw.nhs.uk

Some of the subjects they cover include: stress, sleeping problems, panic, health anxiety, depression and low mood, alcohol and you.

Headway Brain Injury Identity Card

The Headway Brain Injury Identity Card is designed to provide people with brain injuries with added confidence in everyday social scenarios. Each card is personalised, helping the card holder to explain the effects of their brain injury and request any support they may need.

Search for 'brain injury identity card' at www.headway.org.uk



Some examples of when you may want to show your card include:

- in a shop
- using the bus
- struggling to communicate what you mean.

Mind

Mind provides advice and support to empower anyone experiencing mental health difficulties. Some of their guides cover where to find help, bereavement services and finding peer support with others in similar situations.

Visit: www.mind.org.uk

Call: 0300 1233 393

Email: info@mind.org.uk

Text: 86463

Samaritans

The Samaritans offer a safe place for you to talk any time you like, in your own way, about whatever's getting to you. They won't judge you or tell you what to do, they'll listen to you.

They are available 24 hours a day, 7 days a week.

Telephone free on: 116 123

Email them at: jo@samaritans.org

You can also write a letter to them or visit a branch in person. Details are on their website: www.samaritans.org/

In a crisis

If you feel that you are struggling with your mental health please speak to your GP. If you are experiencing a mental health crisis the contact numbers for the local crisis teams are on page 21 in useful resources.

Relaxation, meditation and sleep resources

There are many online websites and phone/tablet applications to help you manage your mental wellbeing. The following are a few examples of well recognised apps, however some require a subscription. You could ask a family member or carer to assist you in finding and downloading these. You may be able to find others for free. Have a search to see what you can find.

Calm: An app for rest, meditation and sleep. www.calm.com

Headspace: An app making meditation simple, teaching you life changing mindfulness in just a few minutes a day. www.headspace.com/

The Happiness Trap: An 8 week online programme to help you reduce stress, relieve anxiety and overcome depression. <https://thehappinesstrap.com/>

Relaxation Techniques – Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust: Audio files of relaxation techniques that can help relieve stress and gain a sense of well-being. Available in both male and female voices. www.cntw.nhs.uk/relaxation



Exercise and activity

Why exercise?

Regular exercise helps to keep your body healthy and prevent other diseases such as heart disease, cancer and diabetes. Exercise produces chemicals in your brain which help improve your mood. It can also help you to sleep better (www.NHS.uk). Exercising and staying active will help you to maintain your current levels of function and for some people it may allow you to continue to improve.

How much exercise?

The Department of Health guidance is that everyone should aim to do:-

- about 20 minutes of exercise every day or five 30 minute sessions, which equals 150 minutes of exercise each week.
- 2 days a week should include strength and balance activities.

What can I do?

There are lots of different options for staying active:

Ways I can stay active

Gym programme (at home or locally) Many have adapted equipment, instructors and schemes for exercising in a supervised way (Speak to your GP about a referral to Exercise on Prescription)

Exercise in water swimming, walking in the water or specific exercises

Exercise through sport e.g. adapted cycling and walking football (see Activity Alliance on the next page).

Exercise in sitting or lying eg seated exercises in a chair or wheelchair

Everyday tasks eg gardening or housework



You may have already been provided with your own personalised exercise programme from your Physiotherapist at Northumberland Head Injuries Service. If so, it is best to follow this as it has been specifically tailored to you.

Chartered Society of Physiotherapy (CSP)

'Love Activity, Hate Exercise?' Is a campaign by the Chartered Society of Physiotherapy, giving advice and guidance on how to become more active, whether at home or in the community.

www.csp.org.uk Follow this link and type **Love Activity, Hate Exercise** in the search box. Select the first option with this title.

Activity Alliance

This charity is dedicated to supporting members and disabled people to make active lives possible. The website talks about many aspects relating to exercising and being active with a disability with ideas and links for other organisations to contact for further information. They are part of the English Federation of Disability Sport.

www.activityalliance.org.uk/

If you have any concerns or questions about exercising, your abilities or limitations you can always discuss this with your GP or Physiotherapist.

Active Northumberland

Active Northumberland are responsible for Northumberland County Council leisure centres etc. You can explore their website which provides all sorts of information about support and classes available. They also have an active at home app that can be downloaded.

www.activenorthumberland.org.uk

What approach should I use?

- **Setting reminders.** on your phone to do your exercises regularly may help you to carry them out. Or you could link them with a daily task such as after going to the toilet or when you first get up.
- **Be realistic.** Find a way of exercising that you enjoy. That way you are more likely to keep it up.
- **Start small.** Set yourself small goals and focus on those 'wins'. You can easily build up from there.
- **Pace yourself.** Little and often is much better than doing all your exercises at once, although this may work for some.
- **Don't give up.** Stay positive and remember how far you've come rather than focusing on what you haven't achieved yet.

How can I exercise at home?

The following websites have videos for a wide variety of activities and exercises you can do at home.

NHS Home Workout Videos

The NHS has created 24 instructor-led videos covering aerobics exercise, strength and resistance, Pilates and yoga at beginner and intermediate levels. These workouts have been created by fitness experts and range from 10 to 45 minutes. Most of the 'move more' exercises are aimed at people who can stand.

www.nhs.uk/conditions/nhs-fitness-studio/

www.nhs.uk/oneyou/for-your-body/move-more/home-workout-videos/

We are Undefeatable

This site contains information for those managing a long term health condition. It gives guidance on finding out what works best for you, including activities and exercises around the home and in the community. It also provides links to YouTube exercise videos for all abilities.

<https://weareundefeatable.co.uk/ways-to-move>

Overcoming MS (Multiple Sclerosis)

Although this is an MS website, the exercises are suitable for people with other neurological conditions and a wide range of activity levels. There are videos for many different exercises: fitness, stretching and strengthening, and many are seated.

<https://overcomingms.org/resources/exercise>

The National Center on Health, Physical Activity and Disability (NCHPAD)

A collection of videos on YouTube for both adults and children. Examples include standing and seated cardio workouts, exercises for people who have had a stroke, strength activities using household items, high intensity workouts and much more! Visit [youtube.com](https://www.youtube.com/user/NCP) and search for 'The National Center on Health, Physical Activity and Disability exercise videos'

<https://www.youtube.com/user/NCP>

Exercise activities on Facebook

Follow '**Active Northumberland**' on Facebook for some simple and effective tips on keeping active at home. Video exercise classes and other activities such as Pilates included. Anyone can access this, it doesn't matter where you live.

Follow '**Make movement your mission**' – 3 times a day short movement classes they call "movement snacks" with adaptations. (8am, Midday and 4pm)

Phone Apps

There are many phone apps that you may find useful. Here are just a couple of ideas:

Step Tracker: A free app on Android phones. It records steps taken like a pedometer. Also measures calories used.

Health: An iPhone app which records health data including the number of steps you take.

Wheelchair Exercises: This is an app regarding exercises and workouts in a wheelchair. All users of foldable wheelchairs, light weight wheelchairs and powered wheelchairs can do it.

Fatigue

Once discharged from Northumberland Head Injuries Service you will continue to adjust to new roles and routines in your life. You may find you become more fatigued during this adjustment. It might be difficult to do all of the things you want to do.

What is fatigue?

It describes an overwhelming loss of energy, a feeling of exhaustion. Many people experience fatigue following exertion (for example, after a busy day at work or doing exercise). Fatigue after brain injury or with other neurological conditions is different to this, it is more intense and long-lasting, and doesn't always get better after resting.

Fatigue can worsen the difficulties linked to your condition, for example forgetfulness, irritability, slurred speech, slowed or 'clouded' thinking and distractibility.

What can I do manage my fatigue?

With time, you will learn to recognise the signs that you are becoming fatigued. You might also want to ask those around you for support – they could help you to notice things that you don't always see.

Understanding your own activity tolerance and signs of fatigue takes time and effort. But, by learning what works (and what doesn't!) you will feel more in control and better able to do the things that are important to you. You will learn to pace yourself.

Signs of fatigue:

- ☐ yawning
- ☐ losing concentration / attention
- ☐ eyes feeling heavy, or eyesight blurring
- ☐ head feeling 'fuzzy'
- ☐ 'zoning out' in conversation
- ☐ struggling with sensory input for example noise
- ☐ fidget / getting irritable
- ☐ limbs feeling heavy
- ☐ stomach feeling sick

Top tips:

Keep a fatigue diary for a week or two: record all of your activities and make a note of your energy levels through the day (eg. 1= no fatigue, 5=extreme fatigue)

Look for patterns and triggers.

Try out some of the strategies in the table below to see what helps you.

What makes things better?

- ☐ Taking regular breaks before I get tired
- ☐ Breaking tasks into smaller chunks
- ☐ Doing one thing at a time
- ☐ Using a timer
- ☐ Prioritising tasks (how important is it? How much energy will it take? How enjoyable is it?)
- ☐ Planning what I am going to do
- ☐ Recognising my achievements
- ☐ Asking for help/ accepting offers of help
- ☐ Using relaxation techniques
- ☐ Breathing slowly
- ☐ Having things to look forward to
- ☐ Eating and drinking healthily
- ☐ Having a good bedtime routine
- ☐ Other things that help me:

What makes things worse?

- ☐ Putting pressure on myself
- ☐ Other people's expectations/ judgement
- ☐ Wanting more of a good thing
- ☐ Getting carried away – losing track of time
- ☐ Impatience
- ☐ Unexpected events
- ☐ Being a perfectionist
- ☐ Loss of motivation
- ☐ Fear of burnout
- ☐ Other things I find difficult:

For further reading, Headway has produced an excellent resource called "Managing Fatigue After Brain Injury", available for free on their website: www.headway.org.uk/media/6580/managing-fatigue-e-booklet.pdf

Reference: Malley D, Wheatcroft J, Gracey F. (2014). Fatigue after Acquired Brain Injury: a model to guide clinical management. *Advances in Clinical Neuroscience and Rehabilitation*. V14(2);17-19.

Memory strategies

Memory difficulties are common amongst people with brain injury and other neurological conditions. This section is written to help you to remember routines and events in your everyday life.

Your Occupational Therapist or Psychologist may have already given you tools to help you with your memory. Now is the time to practice using these strategies in your everyday life.

Internal memory strategies

These memory strategies are 'inside your head'. They are things you do that no-one else can see. Here are some examples:

"I've lost my glasses!"
Let me think... where
have I been? When did I
last use them?

"Everytime I brush my
teeth in the morning, I
must remember to take
my tablets"

"Today is Wednesday.
That means I must put
the bin out tonight"

These strategies 'take up space' in your head. You might find it difficult to hold onto all of the important information you need.

External memory strategies

These are things that you (and other people) can see.

External strategies – or memory aids - are very helpful. They reduce the need to hold things 'in your head'. Everyday examples of this include:

Making a
shopping list

Setting a timer/
alarm

Using a
calendar

Writing a to-do
list

Using
reminders

Task: Which of these memory aids have you used in the past? Which do you think would help you now?

Taking information in

For information to be made into a memory, you must be able to:

- Pay attention to the information
- Make sense of it (information processing)

What can help me?

- Ensure a quiet environment during important conversations – turn off TV/radio to reduce distractions.
- Take notes of key details of conversations. Check with the person you are speaking to that you have understood correctly. Ask for information to be repeated or made simpler if needed.

Build strategies into your daily routine: Once you have decided upon strategies that work – use them regularly. If you use an online or paper diary, make sure you check it at least every day when you wake up. Check it at the start of each week and each month so you can see what lies ahead and plan appropriately.

Be organised: Using memory aids takes time and effort but it is worth it! A **calendar** (on paper or in your phone) is helpful to record an upcoming appointment. An **alarm** is helpful for things in the immediate future – for example an alarm that goes off when your washing machine cycle is done. **Sticky notes** can also be helpful as visual prompts.

Try to focus on a just one or two strategies at a time until they have become a habit.

For further reading visit Headway's website www.headway.org.uk - search for "Coping with memory problems: practical strategies".

References:

Headway (2017). Coping with memory problems: practical strategies. Accessed May 2020: <https://www.headway.org.uk/media/6817/coping-with-memory-problems-practical-strategies-factsheet.pdf>

Malia, K. and Brannigan, A. (2007). Hero's Journey: An educational group Curriculum. Brain Tree training.

Winson, R., Wilson, B.A. & Bateman, A. (eds). (2017). The Brain Injury Rehabilitation Workbook. The Guilford Press.

Making the most of my mobile phone/tablet

Do you have a smart phone or tablet device?

Community access

Using public transport. Finding accessible venues

Rest and relaxation

Apps to help you relax and improve your sleep

Planning

Everything from taking your medicine to managing grocery shopping

Managing finances

Keep track of your spending; help with budgeting

Activities

Brain games to help with attention, problem solving, vision, dexterity...

Education/symptom management

Learn more about your condition



You can download apps onto your device. There are many apps that can help you with tasks in your everyday life.

My Therapy provides a list of NHS-recommended, user-tested apps for people with acquired brain injury. Visit my-therapy.co.uk

Condition specific support groups

The following groups provide support and advice to those with long term neurological conditions. You will be able to find out about other support groups on the internet with help from a family member, friend or professional.

Headway (The Brain Injury Association) - www.headway.org.uk or call 0808 800 2244

Headway is a large national charity who aim to improve the understanding of all aspects of brain injury and provide information, support and services to people affected by brain injury, their families and carers.

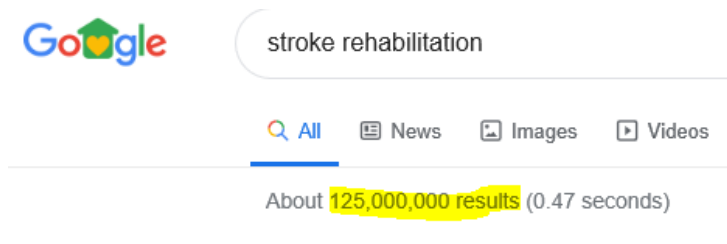
SIA (Spinal Injuries Association) - www.spinal.co.uk or call 0800 980 0501

The Spinal Injuries Association supports anyone who has been touched by spinal cord injury. They work to enable people to live a fulfilled life after injury. Their website has comprehensive advice and support including a telephone counselling service, vocational support and referrals to nurse specialists.

Finding reliable health information on the internet

Finding information about your medical conditions is an important part of self-management. There is so much health information on the internet: you need to know what you can trust.

Where do I begin?



Using a search engine can be a little overwhelming!

Try these trusted websites first. They contain reliable, regulated and safe information.

www.nhs.uk contains information on conditions, treatments, local services and healthy living.

Patient.co.uk uses the same information system that is used in most GP surgeries about conditions, symptoms and medications. Information sheets about most commonly used medicines are also available.

NetDoctor is a website run by a group of qualified health care professionals. It covers information on conditions, symptoms and medications. It is set up to improve communication between doctors and patients.

Ask yourself these three questions



Who?

- * Check the author / organisation
- * Check the 'home' or 'about us' sections
- * Use websites you recognise - such as academic, professional and NHS sites

When?

- * Find the date the page was published / posted
- * Be more wary of information more than 4 years old

Why?

- * Why does this website exist?
- * If it is a company trying to sell something, the information may be biased

Adapted from: Great Ormond Street - www.gosh.nhs.uk/medical-information-0/medicines-information/finding-reliable-medicines-information-internet

Preparing for an appointment

Get the most out of your appointments

You may find this guide helpful to do alongside a family member, carer, friend or therapist (if you are seeing one) so you can get their perspective too.

Before your appointment, think about the following:

- Why are you having this appointment?
- What are your concerns?
- What information do you need to give?
- What information do you want to be given?

What to take with me to the appointment:

- A list of your medication
- Any relevant letters
- This form or a list of your questions

During your appointment

You may want to **ask** some questions:

- Prioritise the questions you want to ask depending on the time you have
- Think about diagnoses, tests, treatment options and follow up
- Ask for copies of letters written about you
- Ask who to contact if you have any more concerns.

Make sure you understand what has been discussed:

- For example, you can say, “Can you explain again?” “I don’t understand” or “What it sounds like you are saying is...”
- Make sure you know what should happen next and who will do it and when.

During or after your appointment you may want to take **action**:

- Write down a summary of what you have discussed and what happens next – ask for help with this in the appointment if you need to
- Write down any further appointments, for example in your diary or phone.
- Put into practice exercises, strategies or suggestions that have been made.

Adapted from Department of Health Leaflet –
Preparing for my appointment.

Useful resources

Apps for wheelchair users or those with who need to consider accessibility in the community.

- iAccessLife - Users can rate and review locations they have visited based on the location's accessibility based on the parking, seating, entrance and toilet. Available for apple devices only.
- Wheelmate is a free app that can be accessed by wheelchair users all over the world. It helps users to find parking spaces and toilets and you can add facilities to it as you find them, to assist others. Available for Android and apple devices.
- If you are a wheelchair user and need an adapted toilet facility with a height adjustable adult-sized changing bench and hoist this website can show you where they are near you. www.changing-places.org/find_a_toilet.aspx

In a crisis

Support provided by Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

If you need urgent help with your mental health right now, you can get in touch with the Trust's Initial Response services. This service is available 24 hours a day, 7 days a week.

Call us on **NHS 111** and select the mental health option.

If you are Deaf or have communication difficulties, you can contact us in a crisis by texting 07860 064 775 or using www.signvideo.co.uk/nhs111

The team does not provide an emergency service such as a 999 response.

Crisis Teams for other areas

- Redcar/Cleveland - 01642 838 300
- Darlington - 01325 552 230
- Durham - 0132 555 2230
- North Durham - 0191 441 5738
- Middlesbrough - 01642 680 706

SHOUT for support in a crisis

Free 24/7 support for people in crisis: www.crisistextline.uk

Text SHOUT to 85258 in the UK to text with a trained Crisis Volunteer.

Further information about the content, reference sources or production of this leaflet can be obtained from the Patient Information Centre. If you would like to tell us what you think about this leaflet please get in touch.

This information can be made available in a range of formats on request (eg Braille, audio, larger print, easy read, BSL or other languages). Please contact the Patient Information Centre Tel: 0191 246 7288

Published by the Patient Information Centre

2023 Copyright, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

Ref, PIC/829/0923 September 2023 V2

www.cntw.nhs.uk Tel: 0191 246 7288

Review date 2026

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