This resource pack brings together a range of resources from NHS organisations, charities and research institutions to support health professionals and people with Persistent Physical Symptoms manage a range of symptoms.

An electronic version of this Resource Pack is available on the Academic Health Science Network website www.ahsn-nenc.org.uk. You can find the project’s pages by searching for PPS. The resources are also available the NAPPS Skills (Northern Association for Persistent Physical Symptoms) pages of the My Health Skills website www.myhealthskills.com

**Introduction**

The resources are grouped into five themes:

1. An introduction to Persistent Physical Symptoms
2. Fatigue
3. Pain
4. Abdominal discomfort and altered bowel habit
5. Neurological symptoms

Each section contains information for health professionals and individuals with PPS and includes leaflets, books, websites, video clips and Apps. The information has been collated using recommendations from local experts and members of PPS support groups.
An Introduction to Persistent Physical Symptoms

Improving Pathways for Persistent Physical Symptoms
Northumbria University, working with the AHSN NENC and the Northern England Strategic Clinical Networks have produced a series of leaflets on PPS. These can be downloaded from the AHSN NENC website www.ahsn-nenc.org.uk You can find the project’s pages by searching for PPS.

For health professionals
We need to talk about symptoms: an introduction
We need to talk about symptoms: consulting and communication skills
We need to talk about symptoms: narratives and explanations
We need to talk about symptoms: a GP perspective

For patients
What’s causing my symptoms?

Christopher Burton’s book, an ABC of Medically Unexplained Symptoms, provides a broad introduction and overview of commonly occurring PPS including headache, pain, fatigue, palpitations gastrointestinal and pelvic pain. The second part of the book considers treatments from a range of perspectives with chapters written by Jon Stone, Christopher Dowrick, David Kernick and Vincent Deary.

The Royal College of Psychiatrists have produced an introductory leaflet on Medically Unexplained Symptoms (2013) available at:
http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/medicallyunexplainedsymptoms.aspx

The Reading Agency runs a national scheme, Reading Well Books on Prescription that helps individuals understand and manage health and wellbeing using self-help reading. It is endorsed by health professionals and supported by public libraries. The core reading list includes titles on chronic fatigue, chronic pain, depression and health anxiety.
https://readingagency.org.uk/adults/BoP%20core%20booklist%20April%202013.pdf
Videos to watch online
Health Education North East funded the Functional Neurological Conditions Special Interest Group of the Northern England Strategic Clinical Network to develop a 10 minute video on functional conditions. In the video local health professionals share their insight and experience in managing persistent physical symptoms.
https://vimeo.com/133129689

Professor Rona Moss-Morris Professor of Psychology as Applied to Medicine, Institute of Psychiatry, KCL has prepared a powerpoint presentation introducing Persistent Physical Symptoms.

Dr Vincent Deary, Reader in Health Psychology in Northumbria University presented at the 2015 British Psychological Society conference on the topic of PPS. You can view his lecture, We need to talk about Anne: Towards a multidisciplinary understanding of human suffering on Youtube searching for ‘DHP 2015 Live – Vincent Deary’.

Providing explanations
For many individuals with changing symptoms or a new diagnosis, repeatedly explaining this to friends, family and work colleagues can be challenging. Cards like the one shown opposite can be a great help for people to explain their symptoms to others.
www.stickmancommunications.co.uk

The ‘Can I tell you about...’ series of books are guides for friends, family and professionals on a range of topics including CFS/ME and depression. The books are very clear and easy to read and can help people understand what it is like to be affected by changing symptoms and conditions.

Using diagrams can also help develop symptom explanations. The Stress Cycle is a useful tool to help people understand the link between physical and mental wellbeing.
Fatigue

The Northern CFS/ME Clinical Network website provides an information resource for practitioners in health, education and social care working with adults, children and young people with CFS/ME across the North of England. The website hosts Dr Gavin Spickett's 2013 revision of guidance notes on the medical assessment of adult patients with suspected CFS/ME http://www.cfsmenorth.nhs.uk/resources-and-downloads

The ME Research UK website hosts a series of seminars presented by Professor Julia Newton. The presentations form part of a project 'Science to Patients', funded by the Dutch government, in which the gap between medical science and patients is bridged by inviting scientists to deliver short webinars on topics of concern to patients. http://www.meresearch.org.uk/news/webinars-by-prof-newton/

The ME Association www.meassociation.org.uk provides information, support and practical advice for people, families and carers affected by ME (Myalgic Encephalopathy), Chronic Fatigue Syndrome (CFS) and Post Viral Fatigue Syndrome (PVFS). The association also funds and supports research, and offers education and training. Their website has over 70 leaflets and booklets, many of which are available to download for free.

Covering the North East and North Cumbria, ME North East www.menortheast.org is a charitable organisation supporting people who are living with ME/CFS and their families. Their website has information on locations and times of support groups across the region.

ActiveME App

http://myhealthapps.net/app/details/191/activeme

The Northern CFS/ME Clinical Network and the Royal National Hospital for Rheumatic Diseases have developed an app to help people with chronic fatigue syndrome track and monitor their daily activity levels. A user picks from four activity grades, and can then record each personal activity (in terms of energy level) on a daily calendar and graph. The app analyses patterns in personal energy levels. Notes can be added in an ‘Energy diary’. Activity patterns can be reviewed, and standards set. The app enables the user to develop a daily baseline of energy levels, suitable for increasing in regular steps. Weekly charts can be emailed in PDF (perhaps to a doctor, or to a carer).
Pain

The pain toolkit www.paintoolkit.org provides information for people who live with persistent pain and healthcare professionals who support them. Information is available online and via an app.

Their work builds from an understanding of the persistent pain cycle. The website has short videos to watch and free to download copies of the pain cycle.

Pain Is Really Strange

This short research-based graphic book reveals just how strange pain is and explains how understanding it is often the key to relieving its effects. Studies have shown that understanding how pain is created and maintained by the nervous system can significantly lessen the pain you experience. This original, gently humorous book explains pain in an easy-to-understand, engaging graphic format and reveals how you can change your mind’s habits to relieve your pain. https://painisreallystrange.wordpress.com
Professor Lorimer Moseley, University of South Australia has given a series of talks on different aspects of pain, many of these are available to watch on YouTube. Two good introductory talks are:

*Pain. Is it all just in your mind?* [https://www.youtube.com/watch?v=-3NmTE-fJSo](https://www.youtube.com/watch?v=-3NmTE-fJSo)

*Getting a grip on pain and the brain* [https://www.youtube.com/watch?v=5p6sbi_0Lc](https://www.youtube.com/watch?v=5p6sbi_0Lc)

The Durham University “It’s a pain” public engagement series focused on the topic of long-term pain management. Links to keynote speaker videos are available via the Durham University YouTube channel [https://www.dur.ac.uk/wolfson.institute/sig/pain/](https://www.dur.ac.uk/wolfson.institute/sig/pain/)

**The ‘Brainman’ Short films**
A series of three short films featuring ‘Brainman’ have been developed by an Australian partnership (GP Access and the Hunter Integrated Pain Service) supported by Professor Lorimer Mosely.

*Understanding Pain in less than 5 minutes* [https://www.youtube.com/watch?v=5KrUL8tOaQs](https://www.youtube.com/watch?v=5KrUL8tOaQs)
This video introduces people with chronic pain to a self-management tool that will help them manage the impacts of chronic pain on their functioning, emotions and interpersonal relationships.

*Understanding Pain: Brainman stops his opioids* [https://www.youtube.com/watch?v=M1I1myFQPdCE](https://www.youtube.com/watch?v=M1I1myFQPdCE)
This video describes why opioids are no longer recommended for chronic non-cancer pain.

*Understanding Pain: Brainman chooses* [https://www.youtube.com/watch?v=jIwn9rC3rOI](https://www.youtube.com/watch?v=jIwn9rC3rOI)
This film focuses on 5 key messages and describes choices made in moving to a more active, evidence based approach to pain management.

1. Chronic pain can change
2. The mind-body link matters
3. Connection is important
4. Moving more, sitting less and sleeping well is an important part of pain management
5. Healthy food is good medicine

**Headache**
Professor Peter Goadsby and Dr David Kernick present a series of discussions on the management and treatment of headache. [https://www.youtube.com/user/DavidKernick](https://www.youtube.com/user/DavidKernick)
Abdominal discomfort and altered bowel habit

Professor of Neurogastroenterology, Qasim Aziz, discusses some of his research that takes place at the Blizard Institute, Barts and The London School of Medicine and Dentistry.

*How the brain and the gut interact*
[https://www.youtube.com/watch?v=AhjbZ4DVCoE](https://www.youtube.com/watch?v=AhjbZ4DVCoE)


The [IBS Network](http://www.ibsnetwork.org.uk) is the national charity for Irritable Bowel Syndrome. The organisation provides information, advice and support for people with IBS and those who care for them. Their website includes free factsheets, symptom trackers and a self-care program that individuals can follow.

The ‘Can’t Wait’ Card Scheme and Radar Keys

For many people with altered bowel habits, finding access to toilets is an incredibly important issue. In the most severe cases, some people are afraid to visit public places in case they experience an episode of incontinence. The 'Can't Wait' card scheme confirms that an individual has a medical condition and indicates that they may require immediate access to toilet facilities. The card can be used to gain access to the toilet facilities of businesses, supermarkets, or other organisations.

Under the National Key Scheme Radar keys have been produced for disabled individuals to gain access to locked public toilets across the country. The keys are extremely useful for urgent access to toilet facilities and are a great source of independence. These locked toilets are situated in a wide range of locations including train stations, shopping centres, pubs, cafes and stores nationwide, and with a toilet finder app, make finding toilet facilities easy for when you need them most. Radar keys can be purchased from a range of charities including the IBS Network and Disability Rights UK [http://www.disabilityrightsuk.org](http://www.disabilityrightsuk.org) A radar key costs about £4.50
Neurological symptoms

Jon Stone’s website [www.neurosymptoms.org](http://www.neurosymptoms.org) provides a range of information for health professionals and patients on functional and dissociative neurological symptoms. You can also view a video, filmed at the 2015 Edinburgh Fringe, showing Jon discussing what functional neurological disorders are and how they are diagnosed. He talks to a patient, Kathryn, who describes her dissociative seizures.

FND Hope [www.fndhope.org](http://www.fndhope.org) is a self-help support website for Functional Neurological Disorder (FND). The website is written by patients, caregivers, doctors and researchers and brings together a collection of resources, videos and guides.

The website [www.nonepilepticattacks.info](http://www.nonepilepticattacks.info) is hosted by a group of healthcare professionals interested in developing effective treatments for non-epileptic attacks. The group includes neurologists, psychologists and psychotherapists experienced in working with patients with non-epileptic attack disorder (NEAD).

Functional Neurology Forum [www.fnforum.org](http://www.fnforum.org) is a multidisciplinary forum for professionals working with patients with functional neurology with details of meetings, news, research and publications.

In the North East and North Cumbria, the Functional Neurological Conditions Special Interest Group of the Strategic Clinical Network is chaired by Dr Jason Price a Consultant Clinical Neuropsychologist at South Tees NHS Foundation Trust. The group has developed standardised information and education material for professionals and people diagnosed with functional conditions.

Their website hosts a range of videos, presentations, weblinks and research papers.

Information for this Resource Pack was gathered in 2015/16. It reflects the views of people with PPS and health professionals working in this field. As many resources are online their location may change and web links may become obsolete.

To feed in your own suggestions of resources or to highlight resources that have ‘moved’ please e-mail [joanne.smithson@northumbria.ac.uk](mailto:joanne.smithson@northumbria.ac.uk)