

# Appendix 2: Organisations Involved

## **British Association for Parenteral and Enteral Nutrition**



BAPEN is a charitable association that raises awareness of malnutrition and works to advance the nutritional care of patients and those at risk from malnutrition in the wider community. BAPEN brings together the strengths of its Core Groups to raise awareness and understanding of malnutrition in all settings and provides education, advice and resources to advance the nutritional care of patients and those at risk from malnutrition in the wider community. BAPEN's Core Groups include:

- Dietitians – The Parenteral and Enteral Nutrition Group of the British Dietetic Association (PEN Group)
- Doctors and Scientists
- BAPEN Medical (mostly doctors)
- The British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN)
- Nurses – National Nurses Nutrition Group (NNG)
- Patients – Patients on Intravenous and Nasogastric Nutrition Therapy (PINNT)
- Pharmacists – British Pharmaceutical Nutrition Group (BPNG)

Its committees include:

- Malnutrition Action Group
- Clinical Guidance and Education
- Programmes
- Quality Group
- Special Interests Group

BAPEN works with all stakeholders, including patients and professionals, healthcare commissioners and providers at local, regional and national levels, and industry to deliver the nutritional agenda.

BAPEN members are passionate about ensuring that good nutritional care is delivered in all health and social care settings and have established the 'BAPEN 4 Tenets of Good Nutritional Care'.

Recent surveys and reports on Nutrition and hydration include:

1. Brotherton A, Simmonds N, Stroud M. Malnutrition matters: meeting quality standards in nutritional care. Redditch: BAPEN, 2012.
2. Russell CA, Elia M. Nutrition Screening Surveys in Hospitals in Northern Ireland, 2007–2011: A report based on the amalgamated data from the four Nutrition Screening Week surveys undertaken by BAPEN in 2007, 2008, 2010 and 2011: BAPEN, 2014.
3. Russell CA, Elia M. Nutrition Screening Surveys in Hospitals in Wales, 2007–2011: A report based on the amalgamated data from the four Nutrition Screening Week surveys undertaken by BAPEN in 2007, 2008, 2010 and 2011: BAPEN, 2014.
4. Russell CA, Elia M. Nutrition Screening Surveys in Hospitals in Scotland, 2007–2011: A report based on the amalgamated data from the four Nutrition Screening Week surveys undertaken by BAPEN in 2007, 2008, 2010 and 2011: BAPEN, 2014.
5. Russell CA, Elia M. Nutrition Screening Surveys in Hospitals in England, 2007–2011: A report based on the amalgamated data from the four Nutrition Screening Week surveys undertaken by BAPEN in 2007, 2008, 2010 and 2011: BAPEN, 2014.
6. Russell CA, Elia M. Nutrition Screening Surveys in UK Hospitals, 2007–2011: A report based on the amalgamated data from the four Nutrition Screening Week surveys undertaken by BAPEN in 2007, 2008, 2010 and 2011: BAPEN, 2014.

[www.bapen.org.uk](http://www.bapen.org.uk)

## **Patients on Intravenous and Nasogastric Nutrition Therapy**



Imagine being unable to nourish your body from normal food and drink...

Instead you have to rely on liquid nutrients being pumped or infused into your body through a tube. This may be enteral or parenteral. This is your lifeline. Hopefully you won't be in hospital but will be in the comfort of your own surroundings.

We welcome and work with healthcare professionals, industry (in relation to products and services) and the general public and of course, PINNT members, both adults and children.

Our aims are to:

- Promote greater understanding of the therapies amongst patients, potential patients and the medical profession
- Provide contact between patients
- Work towards improving homecare services and range of equipment
- Have a united voice to campaign for a better, flexible and safer service

Over the years we have not only brought together patients from around the world, but also doctors, nurses, pharmacists, dietitians and other healthcare professionals, and industry, as well as other charities working in the field of artificial nutrition worldwide.

<http://www.pinnt.co.uk/>

<http://pinnt.com/Home-Artificial-Week/Archive.aspx>

## **Alzheimer's Society**



Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website and more than 2000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive

Alzheimer's Society report – Counting the Cost (2009) examines the variation in the quality of dementia care provided on general hospital wards. It found that the lack of help with eating and drinking was the biggest area of dissatisfaction among carers of people with dementia. Carers complain that the person with dementia might not eat or drink in hospital as there is nobody to prompt them. One carer reported that hospital staff complained that the person with dementia left all their food, despite the carer explaining that the person with dementia needed support to eat.

[www.alzheimers.org.uk/site/scripts/download\\_info.php?downloadID=356](http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=356)

## **Belong**



Belong is a charitable organisation that provides high quality, specialist care for older people in the North West, and are recognised market leaders in dementia care. Belong villages provide a continuum of services that offer a 'home for life' including:

- Households providing 24-hour nursing care
- Apartments where people continue to live independently
- A village centre with a range of facilities open to the public
- Belong at Home domiciliary care

<http://www.belong.org.uk/>

## **British Liver Trust**



The British Liver Trust is Britain's only national charity for adults with all forms of liver disease, existing to improve the lives of people affected by all liver conditions. Our key roles are in education and awareness, support and research. We aim to improve knowledge of the liver within the general public and the medical profession; to provide support through our information line, website, publications and the facilitation of support groups nationwide; and to co-ordinate funding/provide support for research.

Our 'Diet and liver disease' publication can be downloaded via our website [www.britishlivertrust.org.uk](http://www.britishlivertrust.org.uk) or a hard copy can be sent by request via telephone 01425 481230 and email [info@britishlivertrust.org.uk](mailto:info@britishlivertrust.org.uk)

## **The Crohn's in Childhood Research Association**



The Crohn's in Childhood Research Association (CICRA) is dedicated to creating a wider understanding of Crohn's Disease and ulcerative colitis, particularly as it affects children and young adults. It raises funds to support approved medical and scientific research aimed at finding more effective treatments and an eventual cure. In addition to research,

CICRA offers support to children, young people and their families affected by Crohn's or colitis by organising three meetings each year, one in London and two in different regions of the UK. These days offer parents, children and young people an informal day of meeting others and learning more about their condition including 'meet the expert' sessions.

<http://www.cicra.org>

## **CORE (the Digestive Disorders Foundation)**



Core (the Digestive Disorders Foundation) is a national charity working to fight all diseases of the gut, liver and pancreas. We support research that increases our understanding of disease leading to cures and improved outcomes, we provide evidence-based information to patients enabling them to take control of their condition, and we work to raise awareness of digestive conditions.

Core regularly funds research projects that cover the areas of nutrition:  
[www.corecharity.org.uk/archive/research-projects/nutrition-diet](http://www.corecharity.org.uk/archive/research-projects/nutrition-diet).

We are also part of the 'Love Your Gut' group, a collaboration with the IBS Network and Yakult which promotes good gut health linked to diet and nutrition. There are more details at [www.loveyourgut.com](http://www.loveyourgut.com).

## **Dementia UK**



Dementia UK is a national charity, committed to improving quality of life for all people affected by dementia.

We promote and develop Admiral Nursing, through partnerships with host organisations.

Dementia UK also runs a national helpline and email service [Admiral Nursing DIRECT](#), which is for family and professional carers, people with dementia and those worried about their memory. Call 0845 257 9406 or email [direct@dementiauk.org](mailto:direct@dementiauk.org).

## **Malnutrition Task Force**



The Malnutrition Task Force is an independent group of experts across health, social care and local government united to address the problem of preventable malnutrition in older people. The Task Force was established in June 2012 to influence behaviours across the NHS, residential care and in the community, developing mechanisms and collating examples of how to identify, prevent and minimise the risk of malnutrition.

We have drawn together principles of best practice and developed a framework to help those working in health and care settings make the changes needed to counter malnutrition. A series of guides have been developed for hospitals, for care homes, for food and beverage providers and for local communities. All of these can be downloaded from our website.

[www.malnutritiontaskforce.org.uk](http://www.malnutritiontaskforce.org.uk)

## **MENCAP**



MENCAP support 1.4 million people with a learning disability in the UK and their families and carers. They fight to change laws and for improved services and access to education, employment and leisure facilities, supporting thousands of people with a learning disability to live their lives the way they want to. MENCAP is one of the largest providers of services, information and advice for people with a learning disability across England, Northern Ireland and Wales.

[www.mencap.org.uk](http://www.mencap.org.uk)

Death by indifference (2007)<sup>44</sup>

[www.mencap.org.uk/sites/default/files/documents/2008-03/DBIreport.pdf](http://www.mencap.org.uk/sites/default/files/documents/2008-03/DBIreport.pdf)

Death by indifference (2012) Progress Report<sup>45</sup>

[www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%2074%20Deaths%20and%20counting.pdf](http://www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%2074%20Deaths%20and%20counting.pdf)

## **The Patients Association**



The Patients Association is a healthcare charity which for 50 years has advocated for better access to accurate and independent information for patients and the public; equal access to high quality healthcare for patients; and the right for patients to be involved in all aspects of decision-making regarding their healthcare.

By listening to patients, we are able to campaign to improve services. We will work with all healthcare providers to improve services. Very often patients think they are alone with the problem or complaint they have. When patients talk to us we are able to track problems arising in more than one place and realise there is a nationwide issue that needs change.

[www.patients-association.com](http://www.patients-association.com)

[www.thecarecampaign.co.uk](http://www.thecarecampaign.co.uk)

## **University Hospitals London Hospitals NHS Foundation Trust**

University College London Hospitals   
NHS Foundation Trust

UCLH is one of the largest NHS trusts in the United Kingdom and provides first-class acute and specialist services in six hospitals. The Dietetics Department at UCLH is involved in

providing effective, evidence-based nutritional assessment, dietary advice and support to patients, their carers and all staff involved in patient care. The department offers an in- and out-patient service to all six hospitals. The team consists of over of over 30 registered dietitians and two assistant practitioners providing expertise in a wide range of specialties.

<http://www.uclh.org/Pages/home.aspx>

## **Wrightington, Wigan and Leigh NHS Foundation Trust**

Wrightington, Wigan and Leigh   
NHS Foundation Trust

Wrightington, Wigan and Leigh NHS Foundation Trust is a major acute trust serving the people of Wigan and Leigh in North West England. The trust employs over 4000 staff and has approximately 750 beds across three hospital sites and a state-of-the-art outpatients centre.

The Royal Albert Edward Infirmary in Wigan is a redeveloped modern District General Hospital providing a base for emergency and acute healthcare. Leigh Infirmary is our elective diagnostic and rehabilitation site. Wrightington Hospital is a specialist centre for orthopaedic surgery.

The trust is consistently delivering harm free care to >95% of patients as measured by the NHS Safety Thermometer and the work to improve nutrition and hydration is believed to be a contributory factor.

<http://www.wwl.nhs.uk/>

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