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Please NHS and Social Care providers – we want more! More that is of appropriate and consistent nutritional information, care and treatment!

18 organisations representing patients, carers and population groups agree that malnutrition is common, often unrecognised and untreated in children as well as adults and may have severe consequences for the most vulnerable. These organisations also agree that the nutrition information, care and treatment accessed by the adults and children they represent is often in short supply, variable in quality and lacks continuity across health and care settings.

***Improving Nutritional Care and Treatment: Perspectives and Recommendations from Population Groups, Patients and Carers* is published today (20 January 09) by BAPEN and presents the consensus views of 18 charities representing groups potentially at risk of being most severely affected if their nutritional needs are not identified and appropriately addressed. These views were expressed and recorded at a Round Table meeting convened by BAPEN in July 2008.**

Professor Marinos Elia, Chair of the Round Table, current Chairman of **BAPEN** says: "The 'bottom-up' comments recorded in this Report from patients, carers and individuals on their experience of nutritional care and treatment and their recommendations for improving such care are remarkably similar to those provided by the multi-disciplinary professionals with which BAPEN usually works. Our challenge now is to link the two – to deliver the joined up approach that will really make a difference to the nutritional care experienced by families, patients and professionals."

Carolyn Wheatley of PINNT (Patients on Intravenous, Nutrition and Naso-gastric Treatment) and a patient herself says: "The groups represented at the 'Round Table' discovered and agreed that *the same type of problems* with nutritional care and treatment affected us all. This came as a surprise – we all thought we had unique problems around equal access to information, expertise and continuity of care.

It also came home to us that it is not just the child or adult with nutritional issues who is affected but also their family – parents, children, siblings, and grandparents. Health and care professionals need to take this wider group into account."

Rosie Barnes, Chief Executive of the **Cystic Fibrosis Trust** (CFT) comments: "The Cystic Fibrosis Trust welcomes the BAPEN nutrition report, drawing attention to the problems experienced by many people with a variety of health difficulties. In a recent survey conducted by the Cystic Fibrosis Trust, around 35% out of well over 1,000 respondents indicated that they had problems in putting on and maintaining weight. A further 50% reported severe problems with digestion, which sometimes resulted in a hospital admission. Whilst most of these patients said they regularly saw a specialist cystic fibrosis dietitian, there was a worrying number of patients who had not seen a dietitian at all, or had only seen one once in the last year. This is just one example of how poor attention to dietary and digestive considerations may have severe adverse impact on the health of an individual. The BAPEN report tackles the various issues faced by those with

health problems and their nutritional requirements in a thoughtful and sensitive way. This basic aspect of healthcare does need to be given appropriate priority to ensure the maximum length and best quality of life.”

Penny Hibberd, Admiral Nurse supported by the charity **for dementia** says:

“Carers and families see nutrition as an extremely high priority to maintaining health and social contact of the person with dementia. Unfortunately in the experience of Admiral Nurses distress around eating and drinking and malnutrition often goes unnoticed until there is a change in symptoms or carer circumstances. Admiral Nurses consider nutrition and hydration as part of our initial and follow-up assessment of the physical and emotional needs of the person with dementia and their carer. We endeavour to ensure that all health and care professionals we work with are alert to this fundamental issue.”

Professor Marinos Elia of BAPEN concludes:

“As well as improved training, communication and extra resources which do require committed funding, our Report and collaborators also call for a fundamental change in attitude to ensure that nutritional care is delivered with compassion and dignity to all people and patients, no matter their age or health status. The Report reminds us that particular care must be taken of the most vulnerable who may not be able to communicate the need for their own nutrition and hydration.

2008 saw nutritional care edge higher up the agenda with government, policy-makers, regulators and professionals. This Report will contribute to maintaining that momentum and help to ensure that malnutrition which accounts for around 10% of the UK’s total health and social care budget [see note below] is addressed effectively.”

Organisations that participated in the Round Table and the Report are BAPEN, PINNT/HalfPINNT, Age Concern England, Age Concern Croydon, Age Concern Hackney, CICRA (Crohns in Childhood Research), Coeliac UK, CORE (Digestive Disorders), Counsel and Care, Cystic Fibrosis Trust, for dementia/Admiral Nurses, Help the Aged, ILC-UK, Macmillan Cancer Support, Mencap, NACC (National Association of Crohns and Colitis), Parkinson’s Disease Society, Scope.

ENDS/

Note: The cost of malnutrition in 2008, using BAPEN’s ‘MUST’ (Malnutrition Universal Screening Tool) as the main basis for the calculations, has been calculated **at more than £13 billion**, approx 10% of the UK’s total health and social care budget an increase from £7.3 billion figure calculated by BAPEN in 2003 (*Improving Nutritional Care and Treatment: Perspectives and Recommendations from population groups, patients and carers, BAPEN 2009, p.8*).

Available for interview: Prof Marinos Elia (BAPEN), Carolyn Wheatley (PINNT and patient case study), Rosie Barnes (CFT) and Emma Lake (CF expert patient adviser), Penny Hibberd (Admiral Nurse) plus representatives from other contributing organisations concerned with older people, cancer and learning disabilities.

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Improving Nutritional Care and Treatment: Perspectives & Recommendations from Population Groups, Patients and Carers states

- Every child and adult to have the right to nutrition and hydration that meets their individual needs
- Nutrition in whatever form it takes to be enjoyed where possible in an appropriate social setting
- The right food or nutrition support to be provided at the right time in the right way to all individuals at risk of malnutrition with compassion and dignity

And calls for

- Nutritional care and treatment appropriate to each malnourished individual must be built into all appropriate health and social care plans to reflect the policies and practice in all settings.
- Every child and adult requiring care in any setting should be screened for malnutrition on admission with follow-up monitoring and re-screening as appropriate.
- A compassionate and practical approach must be taken in the design and delivery of nutritional care, support and treatment.
- The expert input of carers and other advocates for vulnerable individuals must be taken into account in the design and delivery of nutritional services.
- Those in need of nutritional support together with their family and/or carers should be 'centre stage' with respect to detection and management of malnutrition.
- All those caring for others in all settings – hospital, care homes, hospices, schools and housing – must acknowledge the importance of maintaining nutrition and hydration.
- Those delivering care should be made aware through training of how to cope with the following scenarios
 - (i) Not every child or adult in need of nutritional care is aware of their need for support
 - (ii) Not every child or adult in need of nutritional care can communicate their need for that support
- Education in malnutrition and its impact on all age groups, and how this and other appropriate information is communicated to patients and carers, should be made mandatory for all individuals in a position of care.
- The public should be better informed about malnutrition, its causes and consequences.
- The public should be clear about the standards and types of nutritional care and treatment that are expected in all settings for themselves, their families and for anyone for whom they care.

Further Notes for Editors:

1. *Improving Nutritional Care and Treatment: Perspectives and Recommendations from Population Groups, Patients and Carers* summary is available to download from the BAPEN website www.bapen.org.uk and full Reports to purchase at £20.
2. BAPEN (British Association for Parenteral and Enteral Nutrition) is the multi-disciplinary charity committed to raising awareness of and addressing malnutrition and its consequences and raising standards in nutritional care and treatment across hospital, care and community settings.
3. Professor Marinos Elia retires as Chairman of BAPEN in February 2009 to be succeeded by Dr Mike Stroud of Southampton. Professor Elia takes up the Chairmanship of BAPEN's Malnutrition Action Group at the same time.