A Report from BAPEN
With 18 collaborating partners from the voluntary sector

Improving nutritional care and treatment Perspectives and Recommendations from Population Groups, Patients and Carers

M Elia and R M Smith
on behalf of BAPEN and its collaborators

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A meeting was convened by BAPEN on 1st July 2008 in London attended by 18 charitable organisations representing a wide spectrum of population and patient groups concerned about and committed to improving access to and delivery of the nutrition information, care and support provided to the population group they represent. This Report is the result of the discussion at the meeting, follow-up with organisations represented at that meeting and written correspondence with a number of organisations unable to attend on the day.

BAPEN thanks all participating organisations for the time devoted to this project and to their commitment to the cause of improving nutritional care and treatment.

This Report reflects the wide range of comments and ideas expressed at that meeting and in correspondence but does not necessarily reflect BAPEN's own position or recommendations.

A full list of participating and corresponding participants is provided on page (ii).

Feedback on this Report and its content from other organisations not involved in its development are welcome. Please email the BAPEN Office as above.

BAPEN
Advancing Clinical Nutrition
www.bapen.org.uk
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With thanks to all participating organisations -

Age Concern England, Age Concern Croydon, Age Concern Hackney, CICRA (Crohn's in Childhood Research), Coeliac UK, CORE (Digestive Disorders), Counsel and Care, Cystic Fibrosis Trust, for dementia/Admiral Nurses, Help the Aged, ILC-UK (International Longevity Centre UK), Macmillan Cancer Support, Mencap, NACC (National Association of Crohn's and Colitis), Parkinson's Disease Society, PINNT/HalfPINNT (Patients on Intravenous and Nasogastric Nutrition Therapy), Scope.

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* Rest of content available in the Full Report available from the BAPEN office or at www.bapen.org.uk.

- Organisations contributing to the BAPEN Round Table and this Report represent in excess of 10,000,000 children and adults.
- Organisations involved with the BAPEN Round Table and this Report are in direct contact with in excess of 1,000,000 children and adults each year via memberships, direct activity, and website and/or information exchange.

Document Purpose	**Present consensus views and ideas on nutritional care and treatment from patients, carers and representatives of population groups**
Title	**Improving Nutritional Care and Support**
Authors	**Marinos Elia, Rhonda M Smith**
Publication date	**January 2009**
Target audience	**DH, NHS, SHAs, Trusts CEOs, Commissioners**
Circulation list	**To key personnel of above**
Description	**Report of a meeting convened by BAPEN of 18 population, patient and carer groups**
Cross reference	**Delivery Board of Nutrition Action Plan (DH England); Food, Fluid NHSQIS; NICE Clinical Guideline 32 2006; Essence of Care; Dignity in Care**
Action required	**To review resources, plans, policies and training provision for nutritional care and treatment**
Contact details	**BAPEN Office bapen@sovereignconference.co.uk**

List of Participating Organisations and their Representatives

Further information about and from the participating organisations is available in Appendix II

BAPEN British Association for Parenteral and Enteral Nutrition	Professor Marinos Elia, Dr Simon Gabe, Rhonda Smith
PINNT/Half PINNT Patients on Intravenous Nasogastric Nutrition Therapy	Carolyn Wheatley
Age Concern England	Esmee Russell
Age Concern Croydon	Sue Orchard and Julia Powley
Age Concern Hackney	Shirley Murgraff
CICRA Crohn's in Childhood Research Association	Margaret Lee and Martina Gaffney
Coeliac UK	Norma McGough
CORE Digestive Disorders Foundation	Warren Alexander
Counsel and Care	Caroline Bernard
Cystic Fibrosis Trust	Rosie Barnes, Emma Lake, Carolyn Patchell and Joanna Barrett
for dementia / Admiral Nurses	Penny Hibberd
Help the Aged	Pamela Holmes
ILC-UK International Longevity Centre UK	Lisa Wilson
Macmillan Cancer Support	Jane Hopkinson
MENCAP	Theresa Shepherd
NACC National Association of Crohn's and Colitis	Represented by CICRA
Parkinson's Disease Society	Daiga Heisters
SCOPE	Vicky Keeping

Recommendations

For government and policy-makers

1. Nutrition information, care and support should be considered for inclusion in every child and adult health and social care plan across all settings.
2. Inspection of the policy and practice in all settings must be rigorous and ensure that appropriate nutrition information, support and treatment are being delivered.
3. A robust mechanism must be designed for inspecting and reporting on the effectiveness of 'consistency of nutritional care and treatment' between disciplines and across domiciliary, primary health, housing, care and secondary/tertiary health settings.

For healthcare professionals

4. A flexible and compassionate approach must be taken to the delivery of nutritional care and treatment; this approach should be inclusive of patients, carers and other advocates.
5. All those with responsibility for direct care must receive communication and awareness training to support vulnerable child and adult groups with verbal, physical or cognitive impairments who are unaware of or are unable to express or fulfil their nutrition and hydration needs.
6. Over 3 million health and social care workers across the UK should receive generic training on 'Nutritional care for all' and this topic should be built into the Continuing Professional Development programmes of all disciplines to combat inequality of knowledge, experience, and provision of care.

For public health professionals

7. A public health education campaign on the importance of malnutrition, particularly among vulnerable population groups, is recommended to raise awareness among the UK's population.

For all stakeholders

8. Advantage should be taken of policy and practice initiatives underway across the UK to include nutritional care and support as a key improvement milestone in all those initiatives with a specific focus on malnutrition and improving patient experience.
9. Resources should be made available to deliver the improvements in policy and practice to deliver appropriate nutritional care and treatment for all.

Organisations represented at the BAPEN Round Table meeting recognise that there are a number of valuable initiatives currently underway within and across professional groups and statutory agencies to improve nutrition care and treatment. The organisations represented at the meeting commended these efforts and expressed their willingness to work in the development of such initiatives and to support the positive outcomes and the implementation of all improvements in this area.

However, those at the meeting wished to make it clear that this support from and involvement of charitable and not-for-profit groups should not be viewed as a 'cheap' option by government or other bodies, and did not remove the obligation of central government to provide the framework and resources for the nutritional care, support and treatment required as of right by all children and adults. Neither did their involvement remove the obligation on all providers to deliver that appropriate nutritional care, support and treatment.

Key Messages from participants at the BAPEN Round Table

Notes on definitions

1 Malnutrition is a major clinical and public health problem, but surprisingly there is no universally-accepted definition. It is commonly understood to mean 'undernutrition', which is the way it is used in this Report but it should be noted that even those who are obese may also be malnourished.

2 Nutritional care, support and treatment are used in this Report to mean the full spectrum of all types of treatment, ranging from food and special diets to use of special tube feeds and intravenous nutrition.

3 The word 'malnutrition' may refer in some contexts in this Report and elsewhere to the 'risk of malnutrition' as well as to the presence of malnutrition.

Consensus views on malnutrition and nutritional care, support and treatment

- The groups represented at the 'Round Table' discovered and agreed that *the same type of problems* with nutritional care and treatment affected them all.
- Malnutrition is common in all population and patient groups across all age groups.
- Malnutrition is often unrecognised and therefore remains untreated, which for vulnerable population and patient groups may have severe consequences, predisposing to disease and detrimentally affecting well being and the outcome of disease.
- Not every child or adult in need of nutritional care and support is aware of their need or can communicate this need.
- Malnutrition affects the individual concerned in a variety of important physical and psychological ways.
- The effects of malnutrition are not restricted to those directly affected by it; they extend to carers and families of affected individuals.
- Issues surrounding malnutrition and its treatment can be complex, often involving multidisciplinary care which requires appropriate organisational structures.
- Commonsense generic and holistic solutions involving all types of care workers are required to combat malnutrition across all care settings – community, housing, care, GP, hospital, hospice.
- Malnutrition is a matter for us all, not just the health, dietetic, nutrition and social care specialists.
- There are a range of problems with access to and delivery of appropriate nutritional care and support for both children and adults:
  - The provision of appropriate Information
  - The two-way communication process
  - Identification and diagnosis of malnutrition
  - Support for children, adults and their carers
  - Training in nutrition/malnutrition of all professionals who have a duty of care
- There are significant inequalities in access to and provision of nutritional care and treatment
- Knowledge of and attitude of health and care professionals towards nutritional care treatment is patchy in all settings and subject to a postcode lottery

What do we want?

- 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

How to get there?

- 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.

Education and training for professionals will also help us get there

- All those caring for others in all settings – hospital, care homes, hospices, schools and housing – must acknowledge the importance of maintaining nutrition and hydration, or consideration of its maintenance.
- 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.

Raising awareness will also help

- 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.

Malnutrition and public health

Malnutrition is a major clinical and public health problem, but surprisingly there is no universally-accepted definition. It is commonly understood to mean 'undernutrition', which is the way it is used in this Report.

A broader definition includes both overweight and obesity and specific nutrient deficiencies:

> *Malnutrition is a state of nutrition in which a deficiency or excess (or imbalance) of energy, protein, and other nutrients causes measurable adverse effects on tissue/body form (body shape, size and composition) and function, and clinical outcome* [1]

Malnutrition can be identified by screening tools, which take into account weight status, change in weight and lack of dietary intake. One such tool is BAPEN's 'Malnutrition Universal Screening Tool' ('MUST'), which is now the most commonly utilised in the UK.[2] 'MUST' identifies an individual's risk of malnutrition, but since it establishes the weight status of individuals, it also identifies those who are overweight or obese.

Malnutrition is a burden to patients, health and social services, and society in general, with an estimated public expenditure that has recently been calculated at over £13 billion a year, using BAPEN's 'MUST' as the main basis of the calculations.[3] [4]

The results from BAPEN's Nutrition Screening Week 2007 (NSW07) (data collected September 2007, also based on 'MUST' criteria)[5] established that more than 1 in 4 adults of all ages admitted to hospital and care homes were at risk of malnutrition, the majority at high risk of malnutrition. Most individuals being admitted into hospital and a large proportion of those admitted to long-term care came from their own homes, indicating that much malnutrition starts in the community.

Other studies indicate that at any given time, about 93% of malnutrition occurs in the community, about 2% in hospitals and the remaining 5% approximately equally divided between nursing and residential homes.

Over 3 million adults and children in the UK are malnourished or at risk of malnutrition at any one time with around 1.3 million of these individuals being aged 65 years and over, and the remaining under 65 years. The most vulnerable at risk groups include those with chronic diseases, the elderly, those recently discharged from hospital and those who are poor or socially isolated. There is also an increased risk of malnutrition among those individuals who are unable to recognise their own nutrition or hydration needs, or have difficulty communicating those needs, or in practically feeding themselves.

Malnutrition is frequently undetected and untreated to the detriment of adults and children in community, housing, care and community settings. There are inequalities in the prevalence of malnutrition with the elderly, poor and those living in deprived areas being affected most. There are also inequalities in the provision of nutritional care in care homes and hospitals.

Malnutrition causes a wide range of adverse consequences including the following:

- Impaired immune responses with increased risk of infection and reduced ability to fight it once established.
- Reduced muscle strength and increased fatigue, detrimentally affecting ability to work and independence
- Reduced respiratory muscle function which may lead to increased difficulties in breathing and expectoration, increasing the risk of chest infection and respiratory failure
- Impaired thermoregulation with a predisposition to hypothermia
- Impaired wound healing and delayed recovery from illness
- Apathy, depression and self-neglect
- Increased risk of admission to hospital and length of stay
- Poor libido, fertility, pregnancy outcome and mother child interactions

BAPEN has championed the need for nutritional screening and has developed the 'MUST' for adults for use by health and social care professionals in all types of patient groups in all types of settings. 'MUST' is increasingly used across all four UK nations and it has become a key tool in hospitals in other countries such as The Netherlands. Other screening tools are also in use.

BAPEN is currently working with other agencies to increase awareness of the importance of screening, provide education resources to support the use of 'MUST' and facilitate ways of introducing screening to vulnerable population groups and carers. Caring for the dying patient in Hospice and other settings requires special consideration regarding the comfort as well as the potential clinical benefit that screening and nutritional care can bring.

Once those at risk of malnutrition have been identified, a nutritional care plan is implemented, which may take the form of help with eating and drinking, modified diets, oral nutritional supplements / sip-feeds, or special tube feeding into the gut or intravenous feeding. Re-screening and monitoring must also be included in the care plan.

Improving nutritional care and treatment: BAPEN consultation with population, patient and carer groups

BAPEN as part of its commitment to addressing malnutrition convened a Round Table meeting on 1st July 2008 in London with 18 organisations representing and working with a variety of adult and children's population and patient groups, and their carers, to discuss whether malnutrition was considered to be common, whether problems with delivery of nutritional care were also common, and to establish priorities for improving care.

Specifically the meeting aimed to address the following issues:

Impact and prevalence of malnutrition
Experience of nutrition support and treatment
Improving nutrition support and treatment
Involving vulnerable groups and carers in research and audit
Priorities to improve access to and provision of nutrition care and support

The organisations attending the meeting represented adults and children with learning difficulties, the older population, children with specific conditions such as cystic fibrosis, older people with specific conditions such as dementia and those with specialised nutrition needs. *(See page 4 for details of attending organisations.)*

This Report of the Round Table meeting is being

- tabled by BAPEN as part of its work on the Nutrition Action Plan with the Department of Health in England[6]
- sent to the appropriate government and national agencies in all four UK nations,
- widely circulated to other population and patient support groups for their information and feedback,
- and made available to MPs.

As nutritional issues affect all age groups and are of particular concern to a wide range of vulnerable groups of adults and children, attendees at the BAPEN meeting agreed that an annual meeting to discuss the issues common to them regarding nutrition, including developments following this Report, would be welcomed and supported.

Questions and discussion

The following questions were posed and discussed at the meeting:

Malnutrition

1. Is malnutrition common in your population/patient group?
2. How does malnutrition affect the individuals concerned?
3. How do families/carers view issues concerning malnutrition?
4. Are malnutrition and the issues it generates being addressed in any way by yourselves and/or others?

Nutrition care and treatment

5. Does your population/patient group encounter problems with accessing appropriate nutritional support? What are they?
6. Does your population/patient group encounter problems with the provision of appropriate nutritional support? What are they?
7. Are these issues being addressed or not? If yes who is involved in addressing them, how are these being addressed and are they effective?

Improving nutrition care and treatment

8. What are the real challenges from your population/patients' perspective?
9. What are the opportunities?
10. What is your 'Wish List' and your ideas for improving access and provision?

Research and Audit

11. How does your population/patient group view the collection of information for research and audit purposes?

Consensus

12. What are your population/patient group's top priorities to ensure improved access to and provision of nutrition care and support?

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