Patients’ perspectives of nutrition in IBD

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New name, new logo – same services

We are still legally the National Association for Colitis and Crohn’s Disease

NACC remains the approved acronym among friends!

Please, please never use CCUK

For patients and externally always use

- Crohn’s and Colitis UK
Who we are and what we do

- UK-wide association with 31,000 members, 1,000 active volunteers and 70 local Groups
- Helpline services – Information, Support, Parent to Parent Service and Benefits Support
- Personal Grants for those in hardship
- Publications – DoH (Information Standard)
- Campaigning (Health Services and Living with issues)
- Research Grants – Medical, Living with IBD and Health Services Research

www.crohnsandcolitis.org.uk
Different perspectives on IBD nutrition

➢ Our view as an IBD patient organisation: what should be available.

➢ Individual perspectives:
  ▪ A patient on long-term TPN
  ▪ A patient who has needed ongoing dietary support
  ▪ A patient advocating general nutritional advice
  ▪ Some reflections on ‘food and IBD’

➢ Some commentary on the perspectives
The IBD Standards

- Nutrition support is an integral part of the IBD Standards
- Produced by patient and professional collaboration – incl BAPEN as a supporting organisation
- Included patient views as a starting point for defining an IBD Service
What is important to patients

Key messages from patients were

- the importance of the attitudes of professional staff
- their genuine understanding of IBD
- their respect and support for patients’ making choices about their care
- IBD being seen in the context of the whole life of the patient – not just a medical focus
IBD Standards

Standards launched
February to April 2009

England
Scotland
Wales
N Ireland
The IBD Standards

The six core Service Standards

• High quality clinical care
  • Hospital staff and facilities
  • Multidisciplinary teams
  • Rapid access to treatment etc.
• Local delivery of care
• Maintaining a patient-centred service
• Patient education and support
• Information technology and audit
• Evidence-based practice and research

www.ibdstandards.org.uk
Defining an IBD Service

- **Aim** – to define standards without prescribing the service model in detail, allowing local determination of the best approach
- A defined service – integrated across primary/secondary care and adult/paediatric – with a named clinical lead
- Patient-centred, multidisciplinary approach
- Standards can be met through formal clinical network arrangements
Nutrition in the IBD Standards

• Standard A – High Quality Clinical Care

Rationale : Nutrition

– A significant number of patients who have IBD suffer from malnutrition.
– Nutritional intake and dietary advice are important when patients are admitted, when they relapse and during periods of remission.
– In Crohn’s Disease enteral nutrition can be used to induce remission of disease and is often the treatment of choice in children.
– A proportion of patients, especially inpatients, have nutritional needs that go beyond simple dietary advice and consideration of enteral diets as a primary therapy.
– A multidisciplinary nutrition support team needs to be available for advice on those patients who may require more complex enteral and/or parenteral nutritional support.
Included in the IBD Standards

A1   IBD Team
    ▪ 0.5 wte dietitian for gastroenterology

A2   Essential Supporting Service
    ▪ Nutrition Support Team

A5   Access to nutritional support and therapy
    ▪ From basic advice to nutrition support team

A10  Inpatient care
    ▪ All IBD patients admitted should be weighed and have their nutritional needs assessed

C3   Support for patients’ to exercise choice
    ▪ E.g. between drug and dietary therapy for Crohn’s Disease
Perspective from a patient on long-term TPN

In her words
Summary

- Care provided at specialist centres can involve long journeys, not easy when you are unwell
- No local contact for her IBD care
- Treatment for different associated conditions at different centres; patient is the go-between
- PN always takes precedence over the other problems, which can mean the others don’t get adequately dealt with
• Often has to take the initiative as the patient
• Often feels isolated and quite unsupported
• Expectation by staff that people who have IBD and PN long-term do not need the level of support necessary for recently-diagnosed
• Local IBD Nurse would be best placed to coordinate care for IBD patients who need PN support
A patient who has needed ongoing dietary support
A patient advocating general nutritional advice
Summary

➢ The patient had to ask to try dietary treatment, the choice was not offered.
➢ IBD is lifelong – need for support and advice along the way
➢ Patients can become very uncertain and confused about ‘what is ok’
➢ Specialist advice is needed to counter inappropriate general health messages and myths fostered by media stories.
Key messages

- Dietary advice and nutrition support should be an integral, automatic and regular part of multidisciplinary IBD care.

- Some patients need access to a full nutrition support service offering TPN; they still need:
  - Care from a full IBD Service (care plan)
  - Care as local as possible (network plus care plan)

- Eating and food are an important part of quality of life – sometimes psychological support may be helpful.
Some reflections on ‘food and IBD’ from a patient
Sources of information

➤ For patients:
➤ www.crohnsandcolitis.org.uk
➤ 0845 130 2233 (Mon – Friday 10 am – 1 pm)

➤ For professionals:
➤ www.ibdstandards.org.uk