

Challenges of Managing Adolescents on Modulen® IBD

At a time when adolescents are already experiencing many changes, the challenges faced by the added burden of Crohn's disease shouldn't be underestimated.

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Crohn's disease is a chronic inflammatory disorder which can affect any part of the intestinal tract as well as extraintestinal tissue.¹

A significant part of my role involves managing adolescents with inflammatory bowel disease (IBD) through their diagnosis and ongoing treatment. This includes adolescents who are newly diagnosed with Crohn's disease on Exclusive Enteral Nutrition (EEN), using Modulen® IBD.

WHAT IS MODULEN® IBD?

Modulen® IBD is a whole protein nutritionally complete feed that meets all of the adolescents' nutritional requirements and is taken exclusively for a period of 6-8 weeks.

*'EEN is recommended as first line dietary management to help reduce active luminal Crohn's disease.'*²

The focus on nutritional management in this group of patients is particularly important as they may present at diagnosis in a poor nutritional status. A number of factors can contribute to this, with the main cause being reduced intake secondary to:

- Anorexia
- Nausea
- Abdominal discomfort
- Diarrhoea
- Pain caused by food²

EEN has many advantages including mucosal healing, restoration of

bone mineral density and nutritional status, as well as improvement in growth.³

'Studies have shown EEN may be as effective as steroids in children, but without the usual side effects.'^{4,5}

In particular, the cosmetic side effects of steroids are poorly accepted by adolescent patients.⁶

In Southampton, EEN with Modulen® IBD is commenced in the

hospital environment to ensure the adolescent is adequately monitored and supported until their nutritional intake is established and can be continued at home. To be off food for a period of 6-8 weeks can be a daunting prospect for adolescents. The health care team have a vital role in encouraging and supporting adolescents and their families through this process. A multidisciplinary team approach to their management facilitates compliance with medical treatment. In addition, nutritional support is maximised in a safe environment and disease management optimised.

A VARIETY OF PRACTICAL TIPS* CAN BE EMPLOYED FOR ADOLESCENTS TO AID COMPLIANCE WITH NUTRITIONAL MANAGEMENT:

- Making Modulen® IBD up into lollies or warming to make hot chocolate
- Concentrating Modulen® IBD into lesser volume
- Flavouring the Modulen® with Nesquik®, Crusha or vanilla essence to avoid taste fatigue
- Ensuring Modulen® IBD is refrigerated or transported in cool bags to help palatability. Once made up use within 6 hours at room temperature or within 24 hours if refrigerated. Using opaque sports bottles to disguise/transport Modulen® IBD
- Use of straws to drink Modulen® IBD
- Setting a time frame for drinking Modulen® IBD to avoid rolling one drink into another and ensuring the adolescent has 'break' periods between feeds
- Ensuring other members of the family are on board, keeping the family routine the same; employing strategies to integrate EEN into the family, school and social life
- Make provisions for mealtimes so the adolescent has the choice of being involved to ensure they don't miss out on the social element or become distracted with other activities/interests
- Regular monitoring of nutritional support by a multidisciplinary team

OVERCOMING THE COMMON CHALLENGES FACED BY PATIENTS ON MODULEN® IBD

The challenges faced by adolescents and their families shouldn't be underestimated.

'It is well known that at a time when adolescents are already facing physical, psychological and social development changes, the added burden of inflammatory bowel disease may have significant adverse effects on self-esteem and socialisation.'⁷

Nutritional management necessitating a liquid only diet is a 'big ask'. Compliance can be difficult and may be greatly influenced by the administration route.⁶ In Southampton hospital, we find that most children do not require a nasogastric tube. If utilised, this may lead to body image issues for adolescents.

The health improvements noticed by adolescents within a few days of commencing medical treatment and nutritional management can provide a considerable motivation to continue.

Positive attitudes by healthcare staff and other family members is an added factor contributing to success.

SPECIFIC CHALLENGES

For adolescents, these can include:

- Christmas, birthdays and Easter, when there is a particular focus on celebratory food
- Sleepovers
- Holidays and camping
- Socialising with friends (which often includes eating out)
- Sporting activities

The Child and Adolescent Mental Health Liaison nurses and/or psychologists are sometimes involved to help adolescents come to terms with the diagnosis of a chronic condition: to discuss anxieties, manage compliance, body image, self-esteem and mood issues, as well as empowering adolescents to develop coping strategies.

In terms of materials and resources, more could be done to engage adolescents through social media. This is often one of their main means of communication and through this medium, there is a potential for adolescents to benefit from liaising with other teenagers going through similar experiences.

Adolescents requiring EEN for Crohn's disease can present many challenges for healthcare professionals. At a time when adolescents are already experiencing many changes, the added burden of a chronic disease necessitating nutritional support can be a significant stressor for adolescents and their families. Adequate support and resources are imperative to the success of managing adolescents on Modulen® IBD.

References

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*Based on nurse's clinical judgement. Patient tolerance or suitability needs to be considered.

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Reference: 1. Results from a focus group help at ESPGHAN 2016 - data on file

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