

Maximising diet compliance and palatability

Sue Wood RD, Matthew's Friends Clinics

1st European Conference on Glut1 Deficiency
7th-8th October 2016



No conflicts of interest



Compliance

Compliance / Conformità

- **NOUN**

the action or fact of complying with a wish or command:



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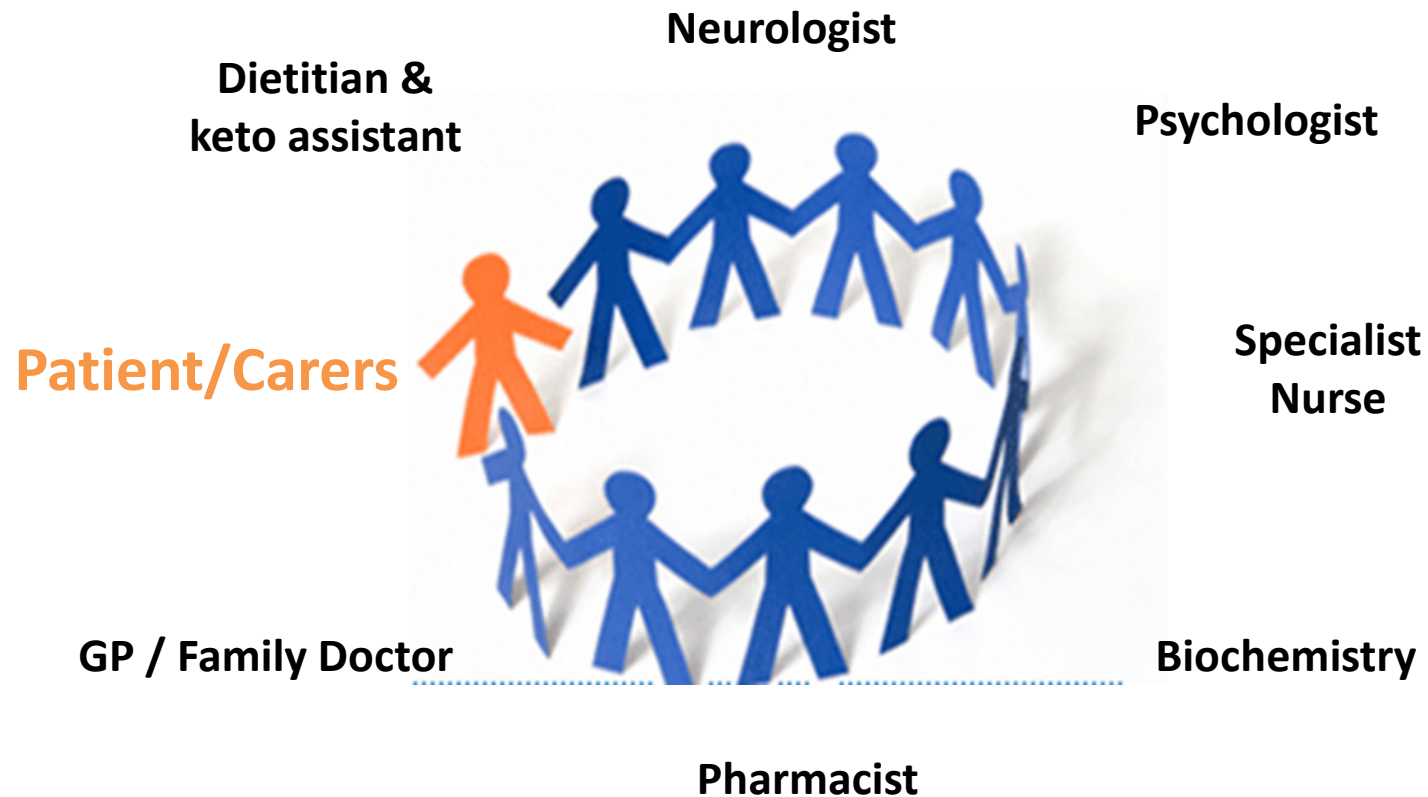


Compliance in ketogenic diet

Co-operation
Ownership
Management
Practical
Linked to others
Inspiration
Adaption to needs
Novel approaches
Continuity of care
Enhance life quality



Co-operation



Ownership & Management

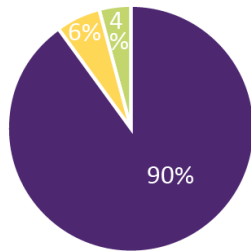
- Understand how food is managed within the family & who is in control?
- Help those in control to understand from the outset:
 - where their potential for control of symptoms lies,
 - the implications of pursuing diet therapy
 - the implications of not pursuing .
- Explain at appropriate level
 - Need to be willing and able!

Family need to be **empowered** to make the therapy **their own**.

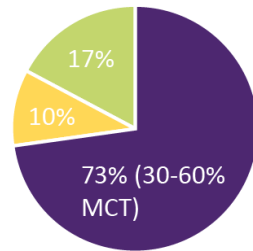
Practical

The right ketogenic approach for me?

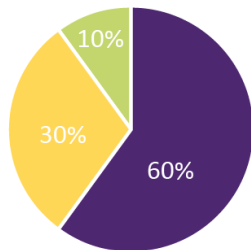
Classical KD (ratio 4:1)



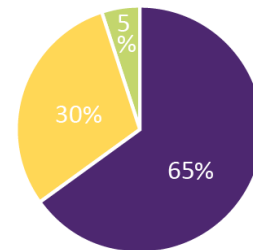
MCT KD



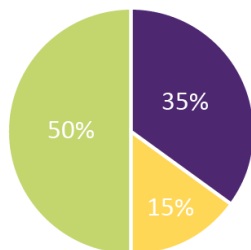
Low glycaemic index diet



Modified Atkins diet (approx ratio 1:1)



Normal UK diet



KEY:

- Fat
- Protein
- Carbohydrate

Fit the diet therapy to the family, not the family to the diet therapy

- *"I have a large appetite and love my carbs"*
- *"I have a small appetite and have little interest in eating at some meals"*
- *"I like to eat with my friends and make my own choices"*

Plus lots of variations..... Eg. MCT oil added into Classical KD/ MAD /LGIT etc

Linked to others for Inspiration

Empowerment through shared learning

- Group support- web
 - National & International Glut 1 organisations
 - Keto support groups / Facebook groups/ recipe sites etc.
- Group support – face to face
 - Encourage learning through attending family conferences etc.
 - Joining families locally for support
 - Cooking demos / using apps to create new meals etc



You are not alone!

Adaption to ability and needs

- Start out simply – build as required
 - food groups ; protein, CHO, Fat
 - Building a meal ... a simple menu
 - Repeat!
 - Expand as confidence grows
- Try to engage family, individual, carers
- Need easy access to practical keto meal advice

First steps : understanding the basics



Novel approaches

Minimal diet change PLUS fat fuel boosters?

- MCT oil /emulsions / powders



- Keto shakes based on food fats : cream /vegetable oils etc or LCT / MCT emulsions or Ketocal LQ



Novel approaches 2

- **Minimal or NO diet change PLUS alternative fuel?????**

Under investigation.....

- Triheptanoin : Clinical trials underway
- C10 / Decanoic acid : Tolerability trial underway in epilepsy
- Ketone esters : ?
- Hashim SA, VanItallie TB. (2014). Ketone body therapy: from the ketogenic diet to the oral administration of ketone ester. J Lipid Res. 2014 Sep;55(9):1818-26
- **Modified Cornstarch?**

Hydrothermally processed high amylopectin starch.

Almuqbil M, et al. (2015).New Paradigm for the Treatment of Glucose Transporter 1 Deficiency Syndrome: Low Glycemic Index Diet and Modified High Amylopectin Cornstarch. Pediatric Neurology ; Volume 53, Issue 3, Pages 243–246

Continuity of care

- Regular medical & dietetic review
- Adjust diet to optimize for:
 - Growth...ages & stages of education & activity
 - Infants
 - Kindergarten
 - Junior school
 - Senior school
 - University
 - Symptom management
 - Lifestyle changes
 - Family changes



Enhance the quality of life



The key to life is balance

Education of others

Fat is my body's favourite fuel!

- Challenge the negative perceptions of others.....
 - Family
 - Friends
 - Health professionals



Factors affecting *compliance*?

- **Demographic & Social factors** 😞 :
 - Cost, ability to cope, other stressors:
- **Psychological** 😊:
 - It makes sense
 - It seems effective
 - benefits exceed the costs
 - ability to succeed at the regimen
 - I feel different from my friends 😞
- **Health care provider and medical system factors** 😊:
 - Social support from dedicated case manager
 - regular/ frequent phone contact with the team
 - good relationship with their doctor (& appointments starting on time!)
- **Disease- and treatment-related factors making adherence more difficult** 😞
 - Chronic health condition
 - Course of symptoms varies or when symptoms are not apparent
 - When a regimen is more complex
 - When a treatment regimen requires lifestyle changes

Delamater AM. Improving Patient Adherence. Clinical Diabetes 2006 Apr; 24(2): 71-77.

Kemper AR, et al. Perspectives on dietary adherence among women with inborn errors of metabolism.

J Am Diet Assoc. 2010;110(2):247-52

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Palatability

Palatability

- Palatability is the **'pleasurable reward'** provided by foods or fluids that are agreeable to the "palate".
- The palatability of a food or fluid, unlike its flavour or taste, **varies with the state of an individual**: it is lower after consumption and higher when deprived.
- Palatability of foods, **can be learned**. May create a pleasure seeking hunger that is independent of homeostatic needs.

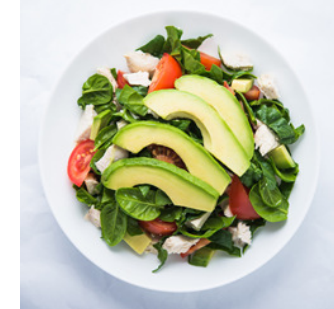


*I don't find spiders palatable
– but some people do!*

Focus on what I can eat and what I like

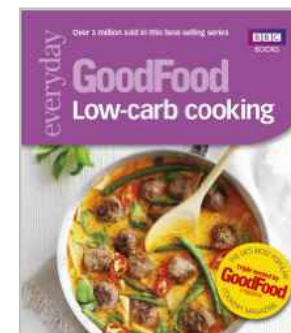
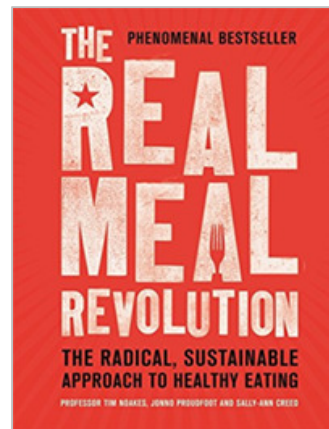
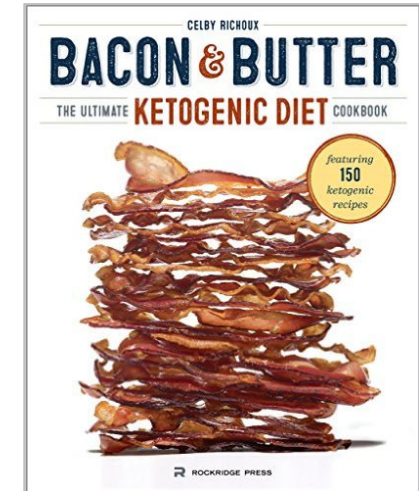
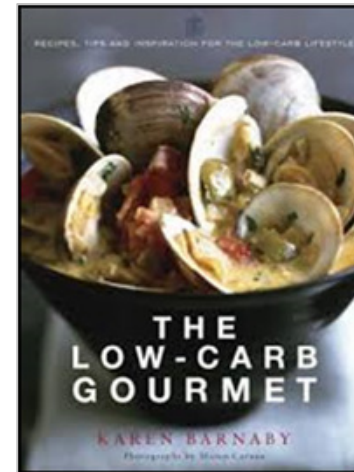
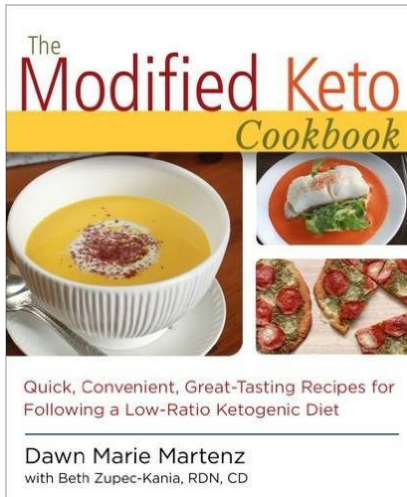
Develop meal ideas that work for me.....

- Breakfast choices
- Quick grab foods
- Packed meals
- Main meals
- Celebration times
- Party with friends
- Cooking at school



Build confidence & a sense of control

Food inspiration : books



Food inspiration : web



Matthews Friends

www.matthewsfriends.org

Charlie Foundation

www.charliefoundation.org

Many other recipe sites eg

www.ruled.me

www.cookinginspiredbylove.com



Easing meal calculations...



NO need to miss out on celebrations!



Summary

To improve long term dietary management :

- Fit the diet around the child, family or adult
- Adapt, adapt, adapt, adapt.....!
- Support from experienced & enthusiastic clinical team
 - PLUS psychological support if possible
- Financial support for specialist products if required
- Encourage links to others – to share ideas and assist problem solving
- Pre-empt age and stage changes

If there is a simpler & effective way, we must offer it!



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Thank you for listening

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The State-and-Region Agreement asks for a declaration by Moderators, Speakers, Teachers and Tutors about the frankness of the financing sources and about their relationships with people with commercial interests within the last two years, only if there could be a conflict of interests.
The documents must be available at the Provider offices for at least 5 years.

Conflict of Interests Declaration

Undersigned _____ **Susan Wood RD** _____ as:

- scientific responsible moderator teacher **speaker** tutor

of the event **“1st European Conference on Glut1 Deficiency”**
Milan - Italy, 7th-8th October 2016

Based on Art.. 3.3 about the Conflict of Interests, page 18,19 of the State-and-Region Agreement dated 19 April 2012,
managed by **Biomedica n. 148**

Declares

- that in the last two years DIDN'T have any relationships about comercial financings with people having conflict of interests in the health field
- that in the last two years HAD relationships about comercial financings with people having conflict of interests in the health field
(please specify the names):

