

LivT1D – Peer support for people with type 1 diabetes

Notes from the LivT1D meeting 28th September 2016, ForeSight Centre, Uni of Liverpool.

Introduction

- The first meeting of the “**LivT1D**” group was amazing. The interaction, the ideas, the enthusiasm and the energy in the room from people with type 1 diabetes was evident from the start.
- There were 10 people with type 1 diabetes present along with Jude Sutton and Emily Barran from JDRF, Reza Zaidi, Fiona Cook and Julie Brake, Sam Scott (PhD student from JMU looking at exercise and type 1 diabetes) and Cath Finlay from Abbott Diabetes who sponsored the meeting.

Presentations

- **Julie Brake (Diabetes Specialist Nurse)** did an introduction to diabetes education locally and nationally and highlighted what the aims of the meeting were. The history of diabetes related education at the Royal Liverpool University Hospital and reasons for not being successful were discussed.
- **Reza Zaidi (Consultant diabetologist)** then did an over view of peer support and the DOC (Diabetes online community) and examples of what support is out there-face to face and online. Advantages and importance of peer-support was discussed and using social media and peer support meetings to learn, share and support people with type 1 diabetes. This was the vision of LivT1D that was presented.
- It was agreed early on that LivT1D was a great name for the group and as a twitter handle @LivT1D.
- Initial discussion around the presentations led to more in-depth talk about the use of social media to support people with diabetes 24/7, how this group could use social media, but also about how more information about using social media and developing and using online support is needed to get the most out of it.
- Twitter, Facebook, Instagram, Snapchat etc were discussed and examples of a patient group setting up a carb counting Facebook page or a LivT1D website/twitter handle.

Focus group feedback

- The attendees in groups of 5 looked at “The Perfect Service” and “Peer Support” and using flip charts wrote down their thoughts and ideas re: these headings which were discussed and summarised at the end.

The Perfect Service

- 24 hour access to a diabetes specialist nurse in case of emergencies by telephone.
- 1-2-1 tuition when newly diagnosed but then maybe teaching classes about the condition
- Social media page run by the clinic, Facebook/Instagram even if used as a notice board about events and having links to information, tips, podcasts, YouTube videos etc
- Offering counselling/mental health services to people with diabetes.
- Outreach service for those newly diagnosed e.g. home visit, as there is a lot to get your head around and take in, and early on this may be better in the patient’s home – or at least given the option.
- 1-2-1 exercise advice or clinics including dietary advice supported by online support www.runsweet.com etc.
- Diabetes “Buddy” system getting support from other people with type 1 diabetes
- Answering machine at the diabetes centre is not good enough as when you call you often need to speak to someone not leave a message.
- More use of **diasend.com** to look at people’s blood glucose testing during telephone and face-to-face visits.
- Also consider providing 1-2-1 sessions for those who cannot attend groups or cannot hear well or communicate well in groups etc
- More freely available advice on how to access support on social media and where to find the info (this is where a clinic social media page/online notice board would be useful) flyers for education sessions and groups.
- More regular appointments or more accessible appointments (for when you need them).
- Better choice of appointment

Peer Support

- Drop in clinics, clinics in other locations- city centre, uni, community centres and clinics that are run not necessarily by doctors and nurses but by other people with type 1 diabetes.
- Maybe drop in clinics provided by meter companies for meter emergencies
- Liverpool based social network
- Plan fun events to raise awareness
- Organise diabetic “get together”, like fun days out.
- 1-1 support from other diabetics, buddy scheme
- Group meetings with guest speakers in a function room so everyone can mingle then sit down and listen, think about accessibility, car parking, public transport access
- Phone calls and texts available from other diabetes patients in the local area
- Carb counting Facebook/Instagram page
- Twitter LivT1 group (This group)
- Excellent idea of 3 monthly meetings
- Flexibility over days and times
- Evening meetings and may be activity/fun days.

- At the end of the meeting the flip chart comments were fed back to the whole group for both headings and both tables. Also Jude and Emily from JDRF spoke to the group and discussed what JDRF do and how they support people with type 1 diabetes. Cath Finlay also talked about the freestyle Libre which a number of people in the room had already used.

Action plan

- **LIVT1D Facebook** page has been created. Please join this, which will serve as a platform to learn and share info.
- **A steering group**, comprising of health-care professionals and patients from this group, will be formed to discuss formation of other social media platforms, organisation of meetings, raising profile and awareness in colleges, universities etc. If you are interested in joining this steering group, please contact Dr.Reza Zaidi (reza.zaidi@rlbuht.nhs.uk) or Julie Brake (Julie.brake@rlbuht.nhs.uk).
- **Posters and flyers** will be created with the help of the Communications/Reprographics team to be used within and possibly outside the hospital.
- **A brief questionnaire** will be sent out to obtain views of what people with type 1 diabetes want developed within this group and what topics need to be presented.
- **3 monthly meetings** will be held in a suitable location in Liverpool, with invited speakers and activities.
- **Next meeting** to be provisionally held in early January 2017. Details to be confirmed.