

The Keep Going.....Don't Stop! group

The Keep Going.....Don't Stop! (KGDS) group was formed in May 2016 with a focus of creating work (related to growing older, dementia and health) that is easily accessible to people with a learning disability in different formats, predominantly Easy Read.

Our aim is to ensure the documents will support people with a learning disability to have more of an understanding of what is happening with their changing health needs as they grow older.

By making the documents accessible, we can make sure we are involving the people we support as much as possible and our staff can be confident that they have the tools to support such conversations.



The KGDS group have consistently consulted with The MacIntyre Checkers to make sure the work being produced is accessible for people with a learning disability, before it is rolled out across MacIntyre services to all staff.

We are also focusing on developing confidence by giving each member of the group responsibilities throughout the day and really involving the team on all that goes on in the meeting. An example of this is making our own lunches from start to finish which is proving to be a real success.

*"Being part of the Keep Going.....Don't Stop! group is interesting and it's something different."
- Heather, a member of the KGDS group*



Creating accessible documents

So far we have created several pieces of work on the topics below that we know will support a person to have more of an understanding of what is happening with their health:

- Accessible Dementia Statements for Dementia Action Alliance
- My health appointments
- What is a good doctor?
- Making an appointment to go to the doctors
- Why am I going to the doctors?
- Planning a visit to the doctors
- Vince has dementia

Setting up the group

We have a small allocated amount of time that needs to be organised to ensure that we can get the most out of each session. To help with this, we have created a workplan so that the sessions run smoothly and stay focused.

As the group meet in Chesterfield, but organisation takes place from Milton Keynes. It has been important to ensure the group is always kept updated with changes that might occur and that staff who support the group members are kept in the loop. Having good communication has meant that each session can take place without any issues arising.

We have learned that it takes time to create really meaningful work. We are producing materials at a slower pace than we initially thought, but the end result is much more significant as it is a collaboration of the thoughts of each group member.

Additionally, some of the content we create can at times be sensitive to discuss, such as End of Life care, so we are mindful that everything we do needs to be explained properly to ensure the group understands and to give the opportunity to share any worries or concerns about the topic.

The work we create is guided by all members of the KGDS group. This collaborative approach is important to ensure everything we create makes sense to as many people as possible and we have been very successful in making sure all voices of the group are heard and that everyone feels comfortable when sharing their opinion.

"I like writing and working as a team with the rest of the group." – Andrew, a member of the KGDS group



"Being part of the Keep Going.....Don't Stop! group makes me think and I like being in the group with my friends." – Andrew, a member of the KGDS group

To find out more or if you have any questions, please contact:
health.team@macintyrecharity.org

Success and achievements

The group has had over 40 fantastic meetings and over this period of time the group has gained trust in each other.

Each member of the group is valued for the work they contribute. For example, each member runs a part of the day, which really boosts their confidence.

This is recognised with praise throughout the year, as well as through a celebration at the end of each year. This celebration makes everyone feel confident and also allows external and internal people to see what the group achieves throughout the year.

The increase in confidence from each individual in the group is the biggest achievement. This is seen not only in the sessions, but also through other activities that the people within the group take part in, both within MacIntyre and externally.

"I like being part of the Keep Going.....Don't Stop! group and I like getting vouchers for the work I do." – Louise, a member of the KGDS group

What's next?

The plan for 2019 is to continue to focus on health and creating a full suite of accessible Easy Read documents that can be used within a service for everyone to use.

These documents are currently in progress:

- Chatty Cards: chatting for confidence
- What is Constipation? A film about constipation
- What is Sepsis? An easy read document

