

Clyde Network

CROSS PARTY GROUP ON IBD

by Edmund Murray

The latest CPG on IBD took place on Wednesday 2nd October at the Scottish Parliament. As usual, it was a busy and informative meeting with a great deal of discussion on the issues raised. The first topic covered was an update on IBD UK and the new IBD Standards. Dr Ian Arnott from Edinburgh's Western General Hospital explained the new IBD Standards and how IBD Services are being asked to benchmark their own services against the new standards to see where they can improve how they currently operate. Next up were Katie Wightman and her mother Fiona talking about their experiences of IBD services and why Katie wants to be involved in helping them improve. Some of Katie's experiences had not been positive and when she spoke you could sense her frustration at what had happened but also her passion for wanting to help change things for the

better. Hearing from IBD patients is vital to the CPG to give their personal experience of both the good and the bad on their Crohn's and Colitis journeys. Last to speak was David Pratt from the Scottish Government taking us through the work being done to develop a new model of care for IBD services in Scotland. This new model is being piloted through three different Health Boards: Borders, Greater Glasgow & Clyde and Lothian, and is at different stages in each due to the timing of when the pilots started. Once all three pilots have been completed they will be reviewed before the final roll-out of the new care model over the remaining Health Boards. It was good to hear that some things which were discussed in previous CPGs had been taken on board within these pilots as a result of the lived experience of patients who had spoken to the Group previously.

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Read the report from the September members' meeting on pages 2 and 4.

NETWORK VOLUNTEER TRAINING by Edmund Murray

On the 14th of September Amy and I attended this year's Network Volunteer training in Edinburgh. We were joined by fellow volunteers from the Durham & Wearside, Edinburgh and Northern Ireland networks as well as Mark and April from Head Office. It was a very interactive day and we all learnt about, and shared plenty of new ideas on how to try different things as a Network.

Over the course of the day, we covered topics such as how to generate ideas for events and awareness raising, engaging with both the Crohn's and Colitis and wider communities and the recruitment and retention of future volunteers. At the end of the training we were all asked to pledge to do something that will benefit the charity's future work. Amy has pledged to start an Instagram page for the Clyde

Network and I've pledged to help the Edinburgh Network grow themselves back up again as they've been struggling recently, through no fault of their own, to put on events. We'll be able to incorporate some of the ideas from the day into how the Clyde Network operates and Amy and I will deliver on our pledges. We're already looking forward to next year's training.

MEETING REPORT 21 SEPTEMBER

by Janice Taylor

Our first speaker was Nancy Greig, of Crohn's & Colitis UK and The ALLIANCE. Nancy is a Health Service Project Manager for Crohn's and Colitis UK and her topic was self-management. She opened with a post-it activity to get us talking, posing the question 'What helps you stay well and manage your condition(s)?' Responses were listed under various themes and reflected a wide range of interests and coping mechanisms. (see the responses on page 3).

What do we mean by 'self-management?'

The term describes the delivery of good practice and support to empower people to manage their own conditions. Crohn's & Colitis UK's 2-year project developing greater understanding of the concept began in 2017, involving patients throughout. Two surveys were organised; one for health professionals and one for people with IBD. Evidence was gathered and focus groups set up in London and Glasgow to explore themes in more detail.

Patient responses to the questionnaire included a desire for more holistic and nutritional care, rapid access to services and emotional support. Health professionals needed more admin and nursing support and resources to aid patients in managing their health. Crohn's & Colitis UK want to see self-management fully embedded within IBD services. The charity's full position statement can be viewed at crohnsandcolitis.org.uk/improving-care-services/self-management.

As stated in the position statement, the vital components of self-management include:

- A responsive IBD service that is

- easy to access when needed.
- Resources to support patients in self-management
- Knowledgeable and confident healthcare professionals
- Good patient/professional relationships
- Quality information and support for people with Crohn's and Colitis to feel empowered and in control
- Access to tools, plans and support to manage treatments, symptoms and flare-ups
- Access to emotional/psychological support
- Access to e-health/technology resources

The next stage was co-designing self-management tools. This involved working closely with the Scottish Government's Modern Outpatient Programme (supporting the ambitions of the Scottish Blueprint for IBD services; www.crohnsandcolitis.org.uk/news/scotland-leads-the-way-in-improving-inflammatory-bowel-disease-services). A workshop held in May 2018 produced two complementary resources:

- A 'flare' card, based on one developed by an IBD team in NHS Greater Glasgow & Clyde. This gives patients actions to help them recognise signs of a flare and what to do about it and is now at the printing stage. A further survey, carried out by IBD nurses in Paisley, who developed the original flare card, was published in *Frontline Gastroenterology*. Results showed that, when taking part in self-management programmes, 82% of patients felt more involved in their care and 100% felt that using the flare card helped them to better-control their IBD.

- A personalised care plan. This encourages patients write about/

reflect on aspects of their daily life and longer-term plans prior to consultations. Thus, IBD staff are made aware of wider issues affecting each patient and together, patients and staff can have more meaningful conversations about what matters to each patient and take shared decisions on best management.

Three pilots to develop new models of community-based specialist IBD nurse care, in the Borders, Lothian and Glasgow are currently taking place. Various models are under discussion, including a plan to put IBD nurses in community health centres, not just in hospitals.

The National IBD Standards were re-launched in June in Glasgow with a focus on personalised care, stating that IBD care should offer a care plan, support in self-management, shared decision-making between patients and health professionals, holistic care, support for pain, fatigue, emotional well-being, diet and nutrition. You can read about the new standards at www.ibduk.org/ibd-standards.

Finally, Nancy encouraged us all to complete Crohn's & Colitis UK's Patient Survey, which has been extended and can be sourced at ibduk.org/ibd-patient-survey

Nancy was asked if all patients would receive a flare card but, although there are plans to roll this out nationally eventually, there are currently two projects in Aberdeen and Edinburgh, where patients are trying them out with the Care Plan. Edmund Murray thanked Nancy for her interesting and informative talk.

ACTION IN MIND TALK

by Janice Taylor

In July I gave a talk to a mental health charity in Stirling called Action in Mind; a non-profit-making support organisation for people who have mental health concerns. It is located in Riverside; a beautiful, peaceful corner of Stirling beside the River Forth, looking towards the Wallace Monument.



Action in Mind organise speakers and activities to support their members and had asked Crohn's & Colitis UK if someone could give a talk about the conditions and the work of our charity. Among other services, they

offer a befriending service and a drop-in centre.

As always, I took along copies of Connect magazine, the Clyde Network newsletter, my 'Can't Wait' card and various leaflets and booklets produced by Crohn's & Colitis UK. I spoke about the work of the charity and IBD, finishing with my own personal journey through illness to happier days.

Two members had relatives with Crohn's Disease, so we had a lengthy discussion about their situations, treatment and, sadly, restrictions on their lives. They took leaflets and membership forms away at the end of the session, which I hope will be helpful to their relatives. We discussed the importance of having an organisation like Crohn's

PASSPORT OFFICE EVENT

Amy Bednarz and Robert Mason from the OT attended an event recently at the Passport Office, which has chosen to support Crohn's & Colitis UK. Robert and Amy manned an information stall and gave a presentation to staff about the charity. Amy also spoke about her own experiences of Crohn's and Colitis.



& Colitis UK to turn to for support and the fund-raising that goes towards research.

I had a very enjoyable afternoon meeting the ladies at Action in Mind and send thanks to Karen for organising the session and Marie for facilitating on the day.

'What helps you stay well and manage your condition(s)?'

Strategies

- Saying 'no' to invitations
- Open communication with employers
- Making positive plans for things to look forward to
- Pacing our lives
- Eating what works for us
- Reading about our illness to increase our knowledge
- Preparing thoroughly for hospital consultations
- Meditation

Hobbies/Interests

- Cats/pets
- Gardening
- Playing the piano
- Theatre/concert visits
- Knitting

Other

- Medication
- Diet & exercise
- Alternative therapies

People who help us

- Family
- Friends
- Doctors/Consultants
- Nurses
- An understanding pharmacist
- GPs
- Support groups, both physical and online

HEALTHCARE IMPROVEMENT SCOTLAND (HIS) TALK

by Janice Taylor

Our second speaker in September was Paul Hayes, from HIS and currently working with Greater Glasgow Health Board. His talk was about 'Person-centred Visiting'. He wanted to use our members as a focus group to discuss ideas around this topic.

Glasgow hospitals are currently reviewing visiting times to wards, to make them more open and patient-friendly. Visiting times, at present, have varied flexibility throughout the hospitals, though mealtimes are usually protected to allow staff to carry out the job of feeding patients, but there is a move to allow visitors into wards when the patients wish to see them, rather than at set times.

Paul's talk provoked lots of opinions, both positive and negative. Concerns were raised about how noisy small, 4- or 6-person rooms could become if one or two patients had too many visitors. It was pointed out that very sick people often find visitors tiring. Might they feel 'forced' to have visitors? Members were worried about how staff would cope with people coming and going throughout the day... and perhaps even night. Would their work be hampered by too many people round a bed? People

also worried about overuse of mobiles in wards, particularly if other patients needed rest. Concerns were also expressed about the staff's ability to eject visitors in the interests of their patients; would relatives and friends listen to staff in these circumstances? Language barriers were also mentioned. Would some patients need a translator? In most wards the doctors' rounds are in the morning. Would visitors perhaps be in the way?

On the positive side it was agreed that the hospital day can be a long one and to have people popping in and out might be beneficial for patients, especially given that staff no longer have time to ensure patients, especially the elderly, are eating properly. Relatives could play a helpful role at mealtimes in these circumstances.

Paul asked the meeting for ideas on what might improve the visiting experience and received a lengthy list of suggestions:

- Better use of day-rooms for seeing visitors
- Tea/coffee-making facilities in day-rooms
- Toys and games available for younger visitors
- Limits on numbers at any one



time

- Co-operation with staff in asking visitors to leave
- Facilities for heating up food
- Regular staff/patient/relative meetings
- A private area for partners to hug or kiss, particularly if one partner is in for a long time
- Enough car parking
- Agreement that the staff's work is important and they must be able to work unhindered
- Wifi that works
- Extra time allowed for staff to manage all this.
- Patient advocates to aid communication with doctors and nurses
- Agreed rest time during the day for patients

In conclusion it was agreed that, to make a success of this project, two things need to be paramount: keeping the patients' needs to the fore and good communication between all parties. Edmund Murray thanked Paul for his interesting talk and the discussion generated by it.



Paul Hayes and Nancy Greig giving talks at the members' meeting in September.

THE GREAT GUTSBY 13: GUT MOVEMENTS

Crohn's and Colitis are life changing, beyond the gut. Going to the toilet multiple times a day, with irregularly-formed stools, accompanied by blood or not, has been the main target of clinician-patient conversations at appointments. However, anyone with Crohn's and Colitis or who has a family member with the conditions knows that Crohn's Disease and Ulcerative Colitis have wider-ranging effects.

I have written before about fatigue, listing brain fog, anxiety, depression, gut pain, joint pain and other co-incidental immune symptoms, such as problems with the eyes and skin. Medication has been devised to treat the bowel successfully but, despite this, life still feels like wading through treacle. Sometimes medication has 'quality of life' side-effects such as insomnia or increased appetite. For each person who has Crohn's or Colitis, some, but not all of these symptoms apply. I have yet to meet anyone who doesn't also live with a secondary effect.

As treatments have encompassed antibody infusions, patients attend hospital day wards (unless they self inject) every few weeks. On infusion days, blood samples are taken and a questionnaire is given, to 'score' how well the bowels are

functioning. The answers achieved are only as good as the questions asked. But what about how Crohn's or Colitis affects your life in other ways?

I mentioned this to a nurse on my infusion day and she told me that they are piloting a new questionnaire for patients with Crohn's. The types of questions you may be asked in the future attempt to encompass the whole person, to try to identify where help may be needed. Looking at how you manage your life around this condition highlights where you might need help.

By asking wider questions, medical teams can see how bowel movements impact on your life, e.g. do you often need to get to a toilet quickly? Are there problems with cleaning yourself sufficiently afterwards? How much pain are you in and when does this mostly occur? In my own case, my diet, what I ate yesterday and when I have used the loo are the most likely things to give me noticeable pain. Sometimes I wonder if it ever really goes away. And for patients with Crohn's, there may also be joint pain.

Then there are the social living changes that the conditions bring. Are you having difficulties with relationships or your social life? Do problems

arise with studying or employment, or getting employment? These show that there are problem areas beyond bowel movements, such as how is your sleep/ how are your energy levels? I have days when I seem to be ok and can do things, but then I hit a wall, like a bunny without Duracell batteries, when all the other bunnies have them.

IBD is already a difficult topic, so some questions may be too sensitive, such as those covering feelings and sex life. Perhaps these are the kind of issues that need to be addressed by psychological services, which ought to be available to all with Crohn's or Colitis.

Clinicians can only assess how well patients are by asking the right questions. In my experience many issues beyond the gut disappear or are reduced if the treatment is right. When my treatments helped stop diarrhoea but nothing else, life was on tenterhooks, and I was more prone to flares. New directions to look beyond the bowel are a big improvement. Perhaps when these are absorbed, there will be patterns in addition to faecal results, to indicate when extra help is needed, keeping us as healthy as possible with these unrelenting diseases. Keep well.

DATES FOR YOUR DIARY

STOMA INFORMATION DAY

Thursday 21 November 1:00-3:30pm
Leapark Hotel, Grangemouth

Forth Valley Hospital stoma nurses are holding an information day, where they will be on hand to answer questions about living with a stoma, preparing for life with a stoma, exercise, diet and other related factors.

POUCH INFORMATION DAY

23 November, 1:00-3:30pm
Jury's Inn, Jamaica Street, Glasgow

Pouch Information Day; a joint meeting with West and Central Scotland Ileostomy Association.

CLYDE NETWORK EDUCATIONAL MEETING AND CHRISTMAS LUNCH

7 December, 1:30pm
Adelaide's, Bath Street, Glasgow

Sarah Sleet, the new CEO of Crohn's & Colitis UK, will give an update on the working of the charity and Sharon Tait will talk on Neuro-Linguistic Programming and Hypnosis.

This year the OT intend to cater for the Christmas lunch themselves and invite attendees to contribute a dish to be shared with members.

Anyone wishing to contribute food for the lunch can contact us on clyde@networks.crohnsandcolitis.org.uk

Those who wish to attend but not contribute food are asked to make a £5 donation towards lunch.

If you have received this newsletter by post and would be happy to receive future editions by email please provide your name, membership number and email address to networks@crohnsandcolitis.org.uk.

This will save the network valuable funds which can be used to benefit all those affected by Crohn's and Colitis.

The Clyde Network has made every reasonable effort to ensure the content of this newsletter is accurate, but accepts no responsibility for any errors or omission. The views of the contributors do not necessarily reflect the views or policies of Crohn's & Colitis UK and no reference in this newsletter to any product or service is intended as a recommendation.

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Charity registered in England Number 1117148

Charity registered in Scotland Number SC038632

A company limited by guarantee in England: company number 5973370

HELPLINE

Our helpline is a confidential service providing information and support to anyone affected by Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD).

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has a personal experience of IBD

CONTACT US BY:

Telephone: 0300 222 5700*

Monday, Tuesday, Wednesday and Friday - 9 am to 5 pm

Thursday - 9 am to 1 pm

Email: info@crohnsandcolitis.org.uk

Web Chat (Live Online): see our website for details

**Calls to this number are charged at a standard landline rate or may be free if you have an inclusive minutes' package. Calls may be recorded for monitoring and evaluation purposes.*

NEWSLETTER

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Design: Jana Moravcova

Print: HH Sign and Print