

Minutes of the Third Meeting of the Cross Party Group on Inflammatory Bowel Disease (IBD)

Wednesday 6 December 2017, 6-8pm

Committee Room 5, the Scottish Parliament

1. Welcome and apologies

Pauline McNeill MSP welcomed everyone to the third meeting of the Cross Party Group on IBD, a warm welcome to those attending for the first time and to MSPs Clare Adamson and Miles Briggs.

Apologies were received from:

Dr Ian Arnott
Paul Johnston
Claire Davidson
Professor Richard Russell
Professor Angus Watson
Dr Johnathan MacDonald
Dr Graham Naismith
Christopher Doyle
Jana Moracova
Kate Gray

2. Minutes of 13th September meeting and actions

Pauline asked for points of accuracy in the minutes of the meeting held on 13th September 2017. No points were noted and no matters arising. The Group approved the minutes.

3. “My Journey with IBD” – Three different stages

Pauline introduced Amelia Yates to the group. Amelia was diagnosed with ulcerative colitis at the age of 10 after having become increasingly unwell over the previous 14 months. Her GP referred for a colonoscopy after six months of worsening symptoms, which at the time of admission resulted in Amelia weighing just 24kg (the average weight of a seven-year old) and passing blood 30-40 times a day.

After the colonoscopy it was suspected that Amelia had Crohn’s Disease and steroids were prescribed. The side effects of the steroids, including anxiety, were difficult for Amelia, however, coming off the steroids meant symptoms came back as she was resistant to them.

Eventually, Amelia was given the choice of trying a new medicine to control her symptoms or having her large bowel removed. Amelia chose to have a subtotal colectomy with ileostomy, naming her stoma ‘Timmy’.

Amelia had the help of the only Paediatric Stoma Nurse in the West of Scotland, which was fantastic support, but her post was part time and when she wasn't working, support was difficult. This was highlighted when Amelia had her first operation for a loop stoma. It leaked from the outset and required to be changed 15-20 times a day as stomach acid was leaking onto Amelia's skin.

As the paediatric Stoma Nurse was not on duty when Amelia went to hospital, the adult nurses tried for 5 hours to find a solution but eventually had to admit her on to a ward. The next day the Paediatric Nurse managed to find a solution and contacted the surgeon to bring forward Amelia's next surgery.

Amelia highlighted the difficulties of dealing with the reactions of her peers at school. She found that at primary school it was easy to explain her condition and be accepted, however, secondary school was a more difficult experience, leading to a lot of anxiety. Amelia has had counselling support which has helped her get over this and is now working hard to become a Paediatric Gastroenterologist when she is older.

Pauline and Clare Adamson MSP both thanked Amelia for sharing her experiences so eloquently.

Pauline introduced Cameron Kelly. Cameron is a 4th year student at Heriot Watt University studying Construction Project Management.

Cameron was diagnosed with Crohn's Disease when he was 10 years old. The thing he remembers most about that day is the shock of seeing his mum cry and not understanding why. Cameron found out later that his mum's friend lived with Crohn's so she knew the journey they were starting on.

Cameron followed lactose free and coeliac diets and then tried a modulin liquid diet. This had an effect on all the family, who were trying to eat without Cameron seeing to avoid him feeling like he was missing out.

While on the liquid diet Cameron tried two drugs which didn't help. He was put on methotrexate injections which left him feeling hung over the day after the injections. After this, infliximab infusions were tried to which Cameron had a frightening allergic reaction which meant he had difficulty breathing. After another treatment proved unsuccessful, the possibility of surgery was mentioned by Cameron's consultant. The treatments and frequent appointments put a lot of pressure on Cameron's parents' work and family life.

Cameron struggled with the idea of a stoma and chose to try medication, however, when symptoms continued, Cameron had the operation during his fifth year at school and went on to sit and do well in his Highers. Friends were very supportive, visiting in hospital, however, Cameron had to give up his favourite pastimes of football and running.

Cameron still has anxiety over access to toilets on journeys including to work and at work in a soft play facility, dressed as a teddy bear, doing children's parties, toilet accessibility was still an issue.

The transition from Children's to Adult services was managed smoothly as two members of staff from Yorkhill attended appointments with Cameron at first.

Having a stoma is still difficult, being a young adult, with the stresses and anxiety around socialising etc.

Pauline thanked Cameron for sharing his story and introduced Steven Sharp. Steven thanked the Group for inviting him to tell his story.

Steven was diagnosed at the age of 12 in 2002. Steven's parents noticed changes in him and took him to his GP. They saw a newly qualified GP who diagnosed Crohn's and referred him to Edinburgh Sick Kids Hospital, where Steven met Professor Wilson and staff who helped him through six years of treatment. Various medications were tried, and each worked for a short time before being rejected by Steven's body. Steven has been left mentally scarred by some of the medications. He still has a fear of milk shakes and finds it difficult to see them, even in shops. The staff at the hospital were a brilliant support to Steven's parents, always available for advice.

At the age of 17 Steven was so thin that his fingers could meet around his waist. Steven made the transition to the adult clinic for surgery, at the time Steven didn't know if it was going to be possible to remove the affected part and re-join his bowel or if a stoma would be required. This transition was difficult as Steven did not know the staff. Children's services were very supportive and adult services seemed scary in comparison. The shock of being moved from High Dependency on to a main adult ward was huge and left Steven wanting to hide behind the curtains in his bed.

Steven has now come out of the other end of his journey and is working and happy.

Clare Adamson MSP thanked all the speakers for sharing their stories and noted how inspirational it has been to have so many people giving evidence to the Group.

Elaine Steven noted that it is heart rending to hear these stories and that young people's experiences have added resonance for those listening.

Lis Bardell commented that as a parent, it is so powerful to hear other families' experiences and how important it is to have the support of peers for young people living with IBD and their families.

Steven said he related to both of the speakers who went before him and Amelia agreed that there is a stigma around the condition. High school has been more difficult than Primary School where her friends and fellow pupils understood about her condition and were supportive. She had heard rumours at school such as: "There's Amelia, she poos out of her stomach."

Pauline said that the Cross Party Group must publicise the problems and urge more understanding to help prevent the stigma.

4. Burdens for paediatric IBD care in Scotland in 2017 – Professor David Wilson.

Professor Wilson's presentation will be made available to CPG members. Some of the key points he covered were:

- Data on incidence of IBD in the adult population is very difficult to collect due to numbers being so high.
- Data for children and young people is good, and it shows a 2 fold increase in the incidence of IBD in the last 45 years in the UK and 4.5 fold increase in Scotland in the same period.
- Adult services which are already stretched will become more stretched as the children transition into adult services.
- IBD is a common disease, however, not a simple condition, with no cure at the moment. Some people have a genetic susceptibility, but environmental triggers are very difficult to pin down. 240 different genetic areas have been linked to the conditions.
- Advances in drugs have kept the cost of IBD the same as they were 10 years ago. New medicines are expensive but they have cut down on harrowing emergency surgery.
- Transition from children's to adult services is a critical time for patients and work is ongoing to make this better.
- The National Blueprint for IBD in Scotland is an excellent document and a validation of the work being done.
- The recommendations from the Blueprint have been translated into policy and in the West of Scotland this has resulted in the problems around testing for *Clostridium difficile* being addressed.
- Paediatric IBD services are evolving, however, services are finding it difficult to provide 24-hour support for Children and Young People and their families. Clinicians would like to provide 24 hour phone or email service, but staffing issues and problems with NHS IT security mean that it is not possible for clinicians to contact patients and families via email.
- Young adult clinics for 16–24 Year olds do not happen as standard in Scotland. It would be difficult for adult services to accommodate more clinics as they are finding it hard to see adult patients due to numbers. We are unable to say how many young people are not being seen by paediatric services as this data is not available.

- The SE Scotland Regional Paediatric Gastroenterology Network is the only region without a dedicated 24/7 rota- instead the general medical paediatrician and paediatric surgeon are asked to cover. Clinicians would like to provide a rota and do see patients and do procedures on an unofficial basis at the moment. This has been raised with the management team at NHS Lothian as a clinical governance and patient safety risk.
- The West of Scotland (Glasgow) and North of Scotland (Aberdeen) networks have defined PGHAN rotas, however, this still means that over a quarter of Scotland's children and young people are denied access to appropriate services outside of 'office hours' without the goodwill of clinicians.

Pauline thanked Professor Wilson for his presentation and asked for questions from the group.

Dr Dagmar Kastner commented that it is difficult to have time to see patients due to sheer numbers and is not possible for adult services to provide walk-in or phone access to clinicians. This comes as a shock to young people transitioning to adult services who have had this access to children's services and then need to be referred through their GP to adult services. There is definitely a need for more transition clinics as paediatric services are not appropriate for 16-24 year olds.

Pauline McNeill asked if transition (16-24) clinics are something to be discussed or are they are impossible to accommodate.

Dr Dan Gaya said that at the moment return appointments are currently 11 months as a result of the current target driven system. Transition services are easy for the patient if they are well but if the patient is unwell and needs to access adult services urgently it can be a real shock. He thinks change is unlikely to happen as a result of political discussion, more that clinicians will establish the clinics and make them happen then the funding will follow.

Action: It was suggested that the group invite the Cabinet Secretary for Health to attend a future meeting to discuss 16-24 transition clinics.

5. How Crohn's and Colitis UK supports children and families – Elliot James, Young People and Families Development Officer

Elliot gave an overview of the support Crohn's and Colitis UK provides for Children Young People and Families.

This includes:

- Family Days supported by clinicians which introduce patients to each other allowing for peer support and access to clinical advice.

- Specific adolescent sessions were held at the Glasgow Family Day in September 2017. These were very well received and more are planned.
- Partnership work with Over the Wall (a children’s charity who provide free of charge therapeutic recreation camps to help children with life-limiting illnesses and their families) to provide opportunities for young people and families to meet and have a weekend away.
- Information leaflets which were created with contributions from clinicians to provide information for young people and families. These include:
 - Parents’ guide
 - Fact sheets for schools, universities and students
 - Adult fact sheets are being adapted to make them relevant to young adults
- A new app being developed to make information easily accessible on mobile phones.
- Political campaigning and work with stakeholders continues. The local network in Scotland is driven mainly by volunteers.
- Young ambassadors are sent to Europe annually to share experiences and work on the Pan-Europe Transitions Programme.
- Videos have been produced of short films with advice on how to live with IBD and uploaded to You Tube to target young people.
- Developing volunteering opportunities for children and young people.
- An Over the Wall camp is being planned in Scotland for 2019.
- Targeted membership packs are sent out to each new member which include a RADAR key and “Can’t Wait” cards.
- Lots of new communication work is being planned to target information to 16-24 year olds.

Miles Briggs MSP left the meeting at this point.

6. Discussion and actions

Clare Adamson asked how clinicians got information and advice to patients from NHS clinics.

Vicky Garrick (paediatric IBD Nurse) explained that in her clinic they run email clinics using a generic email address. The initial email contact asks for the patient's permission to discuss their condition.

Clare is interested in exploring a secure way to communicate with patients and suggested this would be another thing to discuss with the Cabinet Secretary or Minister at a future meeting.

Janice Taylor mentioned that she has had experience of receiving bounce backs from IBD nurses' email accounts as mailboxes are full. There was a discussion around issues with the NHS email system due to small mailbox capacity and firewalls blocking anything with an attachment or hyperlink. This has all been heightened since the well-publicised data breach earlier this year.

Gail Grant mentioned the Health and Sport Committee Inquiry looking into technology in the NHS. It was confirmed that Crohn's and Colitis UK have fed into this inquiry and the Cross Party group has provided supplementary evidence.

Angus McLean suggested that Skype could be usefully used for appointments.

Elaine mentioned that there is a specific software package designed for appointments called "Attend Anywhere".

Dagmar highlighted that Aberdeen services use Attend Anywhere virtual appointments and have developed a video protocol which could be shared with the group.

Action: Include the role of IT in IBD services and access to services in the work plan for 2018

Lis commented that the practicalities of dealing with the emotional effect of IBD are very difficult and wondered if it would be possible for the group to explore this more.

Nancy Greig said that the next meeting of the group will focus on psychological support and self management. Speakers for this meeting are not confirmed yet.

Elliot mentioned that Crohn's and Colitis UK offer some emotional support over the phone at the moment and the potential might be there to grow this service subject to budgets. Elaine mentioned research on psychological support for people with IBD by Dr Georgina Rowse, who is working on a project with Crohn's and Colitis UK.

Amelia asked to re-iterate the importance of the emotional and practical support offered by paediatric IBD nurses, saying that the day her Stoma Nurse, Jenna was off was the worst day of her whole experience, but that within 24 hours Jenna had found a solution to her problem.

Pauline thanked all the speakers for sharing their experiences bravely and assured them that doing so will help lots of others in similar situations.

7. Work plan for 2018/9

Due to time constraints this will be discussed at the next meeting.

8. Date of next meeting

Wednesday 21st February 2018, 6-8pm, Committee Room 5.

Attendance List

Members:

Pauline McNeil MSP (Convenor)

Clare Adamson MSP (Deputy Convenor)

Miles Briggs MSP (part of the meeting)

Kirsty Gibson

Angus MacLean

Edmund Murray

Dr Daniel Gaya

Professor David Wilson (speaker)

Vikki Garrick, Scottish IBD Nurses Network

Seth Squires, Scottish IBD Nurses Network

Allan Boal, Scottish IBD Nurses Network

Pam Rogers

Gail Grant, Abbvie

Sally McNaught, CICRA

Janice Taylor

Nancy Greig, Crohn's and Colitis UK

Elaine Steven, Crohn's and Colitis UK

In attendance:

Elliot James, Crohn's and Colitis UK (speaker)

Cameron Kelly (speaker)

Steven Sharp (speaker)

Amelia Yates (speaker)

Lucy Yates

Jordan Hope

John McArthur

Dr Dagmar Kastner, NOSPGHAN

Cher-Antonia Khedim

Chris Hansell

Susan Brooks (minutes)

Pamela Smith (Pauline McNeill's office)

Lis Bardell (Clare Adamson's office)