

# This house believes the IBD nurse advice line is essential to any IBD nursing Service

Aileen Fraser

IBD CNS

Bristol Royal Infirmary

Over the past three years, I have received remuneration from the following companies:

- AbbVie
- Actavis
- Allergan
- Dr Falk Pharma
- Ferring
- Janssen
- Pharmacosmos
- Shield
- Takeda UK Ltd
- Tillotts

- Advice lines for patients with IBD are vital

# Why?



# Because they are part of the standards

University Hospitals Bristol  
NHS Foundation Trust



## IBD Standards

Section 1: The IBD service

Section 2: Pre-diagnosis

Section 3:  
Newly diagnosed

### Statement 4.3

Rapid access to specialist advice should be available to patients to guide early flare intervention, including access to a telephone/email advice line with response by the end of the next working day.

Respecting everyone  
Embracing change  
Recognising success  
Working together  
**Our hospitals.**

# The patients love them

## What are advice lines for?

They're for IBD patients who:

- ✓ Are having a flare-up or worried about adverse symptoms
- ✓ Are in between appointments
- ✓ Need advice direct from an IBD Nurse Specialist

They shouldn't be used:

- ✗ In an emergency / as an emergency contact
- ✗ To arrange or change routine appointments
- ✗ For more general information about IBD

For more general information about [Crohn's Disease](#), [Ulcerative Colitis](#) and other forms of [Inflammatory Bowel Disease \(IBD\)](#), patients can contact the [Crohn's and Colitis UK information service](#).

# They reduce your workload

University Hospitals Bristol  
NHS Foundation Trust



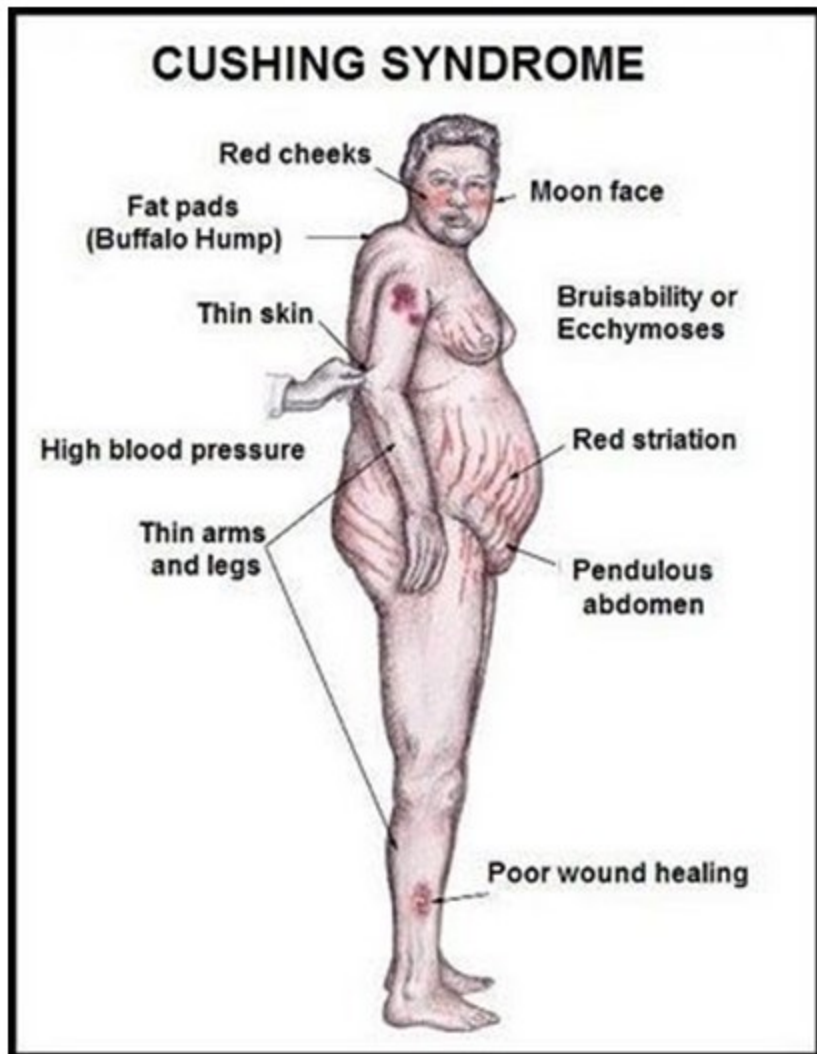
- You would need to do far more clinics



Respecting everyone  
Embracing change  
Recognising success  
Working together  
**Our hospitals.**

- And to pick up the pieces from patients having too many steroids...

Not to mention what effect they have on bones and brain!



- Increased Emergency Department visits



(That's the patients and you)

- Vastly increased GP calls/letters to you and to your medical colleagues for advice
  - And you know how easy it is to get back to a GP on the phone



- Advice lines are hard work and can feel like an Albatross around your neck



- Keep in mind how important they are for the patients and for us as clinicians
  - Ease of access to specialised care
  - Keeping patients out of the GP's practice and out of A&E
  - Reducing clinic burden
  - Giving patients confidence to manage at home as they know they can contact us.

# A final thought

- CM
  - 31 yr old male teacher
  - On PO methotrexate weekly
  - Colonic crohns
  - In remission

06/02/2009

Friday afternoon (obviously)

University Hospitals Bristol  
NHS Foundation Trust



- Called the advice line
- Girlfriend is 4-6 weeks pregnant
- Has just read the insert of his MTX
- Planning a TOP, OPA arranged to discuss this next week

- Asked him to give me time to discuss with foetal health – fairly sure that TOP unnecessary
- Discussed with foetal health consultant, TOP unnecessary.
- Arrange appt for CM and girlfriend with foetal health consultant the following week.

# Outcome

University Hospitals Bristol  
NHS Foundation Trust



Respecting everyone  
Embracing change  
Recognising success  
Working together  
**Our hospitals.**

- Advice lines are vital
- They do save time
- We need see them as vital and have them properly resourced

# IBD Advice lines: Fit for purpose



# IBD Advice lines: Is it time for change?





**Kath Phillis – Advanced IBD Clinical Nurse  
Specialist/IBD Clinical Lead  
Chesterfield Royal Hospital**

# Disclosures

- Trainer and consultant for Tillotts LOGIC IBD Nurse Education modules

# Show of hands

- Who here operates an IBD advice line service?
- Who here feels it is working to it's full potential?
- Who here thinks it is an 'abused' service?
- Who here finds it overwhelming and at times soul destroying? ☹
- Who here thinks it is time to embrace a change in attitudes and behaviour when it comes to the IBD advice line service?

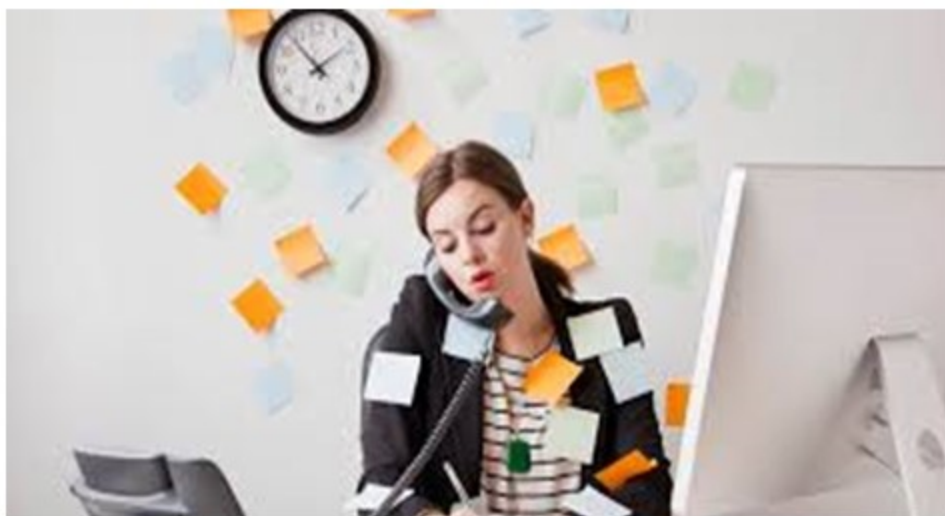




Not to scrap the IBD advice lines.....

But.....

To review, audit, develop operational policies to support the service and our practice and to also develop boundaries to protect us and our patient's.





GO/2208/2019/UK  
September 2019



# One rule for one and one for others

- > 300 IBD nurses working in the UK (CCUK)
- 98% have advice lines
- Only 10% have had any formal training (CCUK)
- IBD advice lines take up a huge majority of the working week hours
- Huge variations in practice - specific hours to call back, messaging service, answering calls at certain times, length of time to return calls, service suspension for annual leave and/or other clinical duties
- Few of us have dedicated admin support
- Lone workers or IBD nurse numbers not in line with what is currently recommended
- Some charge for advice lines/some can't
- Caseloads exceeding nurse numbers
- Limited access to primary care appointments



September 2019

# RCN Facebook IBD Forum

567 members (as of the 26th August 2019 - some non UK nurses)

10th of July 2019 =

- Do you have an IBD advice line? = 88
- Do you ever suspend your advice line? = 30
- Do you have an up to date/regularly updated operational policy? = 13



# RCN Facebook IBD Forum

3rd August 2019

*What is the average time for you to return your advice line messages?*

- Less than 24 hours = 30
- Within one working day? = 5
- 24 - 48 hours = 54
- 24 - 72 hours = 1
- 72 + hours = 7
- Advice line suspended = 0



***"Abused"***

***"Overwhelming"***

***"Over sold and understaffed"***

***"Hard work but rewarding"***

***"Requires a full time nurse to run it properly!"***

***"Unpredictable and very hard to manage"***

***"Appreciated (generally)!"***

***"Failing!!"***

***"Demanding"***



# Surprised (or maybe not!)

- Some nurse are cancelling clinics pre/post annual leave to help deal with the calls and workload
- Some don't record calls and outcomes
- Many have never audited their calls
- Nurses returning calls from home
- Nurses returning calls during conferences/study leave/annual /leave or when off sick (*how many of you here today have taken a work related call/email/text ?*)
- Variations in practice
- No formal training for IBD nurses unlike those that work for CCUK



***“Invaluable!” 😊***



## 2019 IBD Standards



## THE IBD SERVICE

The IBD Multidisciplinary Team  
Patient Engagement  
Service Development  
Electronic Management and Data/Registry  
Provision of Information  
Investigations and Treatment  
Training, Education and Research

## PRE-DIAGNOSIS

Pathways and Protocols  
Faecal Calprotectin  
Timelines for Referral  
Appropriate Expertise  
Information

## NEWLY DIAGNOSED

Shared Decision Making  
Holistic Assessment  
Care Plan and Treatment  
Information and Support

## FLARE MANAGEMENT

Pathways and Protocols  
Information to Patients  
Rapid Access to Specialist  
Advice and Treatment  
Steroid Management

## SURGERY

Multidisciplinary Working  
Surgery by Specialists  
Information & Psych Support  
Laparoscopic Surgery  
Post-operative Care  
Waiting Times

## INPATIENT CARE

Direct Admission to GI Ward  
Access to Toilets  
24 Hour Critical Care  
Assessment  
Access to IBD Nurse  
Discharge Planning

## ONGOING CARE

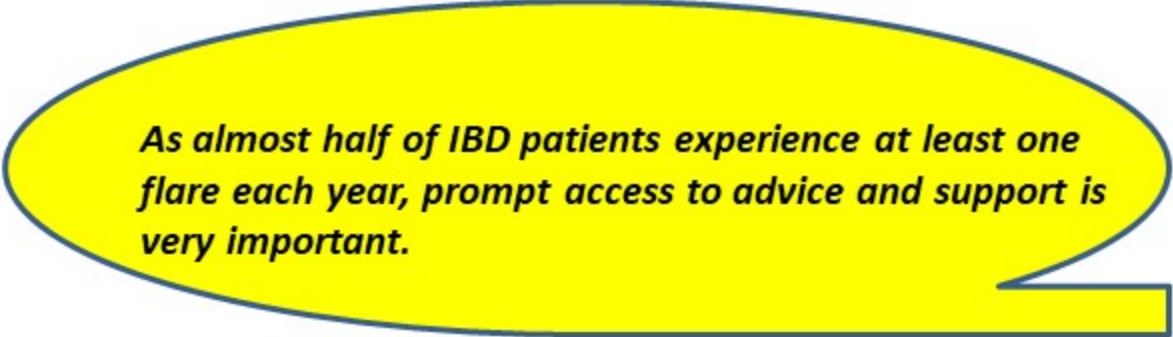
Access to IBD Team  
Personalised Care Plan  
Education/Self-Management  
Pain and Fatigue  
Shared Care  
Ongoing Review

**Statement 4.3**

Rapid access to specialist advice should be available to patients to guide early flare intervention, including access to a telephone/email advice line with response by the end of the next working day.

**Statement 4.4**

Patients with IBD should have access to review by the IBD team within a maximum of five working days and be able to escalate/start a treatment plan within 48 hours of review.



***As almost half of IBD patients experience at least one flare each year, prompt access to advice and support is very important.***

# Demand is ever increasing





Clear Expectations  
+  
Clear Communication

---

Clear Outcome

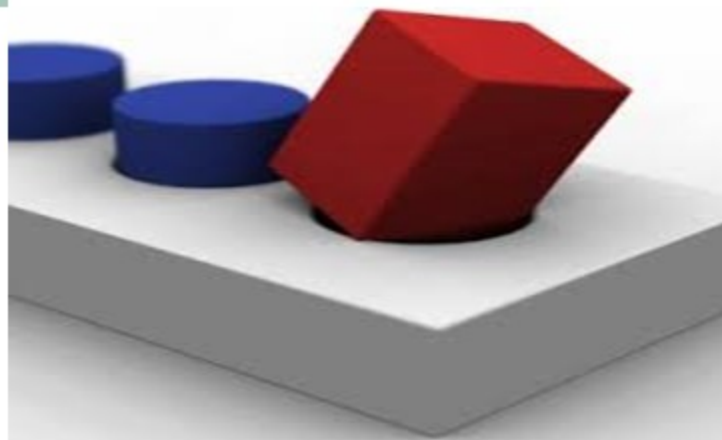
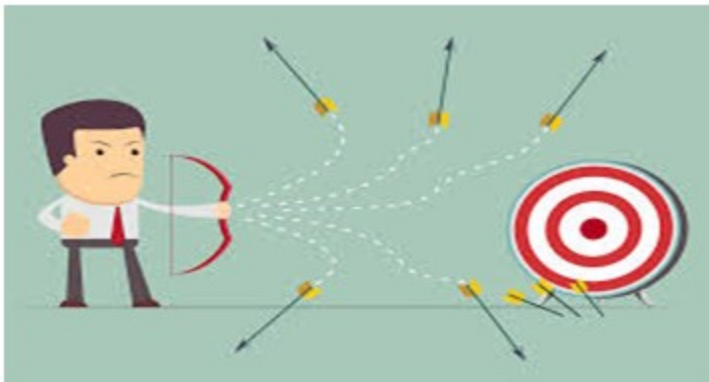
# On a personal note

- Advanced IBD CNS/Clinical lead for approximately 1600+ patients with a diagnosis of IBD
- Working alone until November 2019
- Full time over 4 days
- 4 clinics – 8 – 12 FUP and 4 new slots per week – all overbooked
- 1 x flare slot per week!!!!
- Line manage IBD CNS, Liver CNS and upper GI CNS
- Coordinate/prescribe majority of the Biologic prescriptions
- 6 consultant colleagues – no clinic availability
- Medinet locum until end of 2019



GO/2208/2019/UK  
September 2019

# CRH's Advice line



# My reality – and no doubt yours!

- Answerphone service – Mon, Tues, Thurs, Fri
- Average currently 3 – 8 days to reply
- 50% of my working week is in clinics
- Line management
- Senior matron responsibilities/expectations
- Consultants rely heavily on me
- Biologic pharmacist support
- IBD CNS 22.5 hour week (only 5 hours office based)
- Limited admin support
- IBD Clinical lead









# What's the solution?



# My advice is - don't be afraid to:

## Review your service and ask yourself

1. Is it fit for purpose?
2. Is it functioning to its full potential?
3. Is it effective?
4. What are the bottle necks?
5. How can it be streamlined?
6. How can it be sustained?
7. Have you the staff numbers and staff with appropriate skills to deliver the service?
8. Is it time to suspend the service?





GO/2208/2019/UK  
September 2019

# How do we change old ways?

- Audit – your moans and groans wont be backed up otherwise
- Suspend your service – allow time to review/audit and change practice
- Change/review the parameter's – just because the IBD Standards say 24 hours/next working day it isn't the law!
- Team updates – ensure everyone is updated
- Review and update the operational policy/SOP to fit with current practice
- Signpost patient's elsewhere – CCUK
- Promote your service – reach out to the wider population



# Process mapping

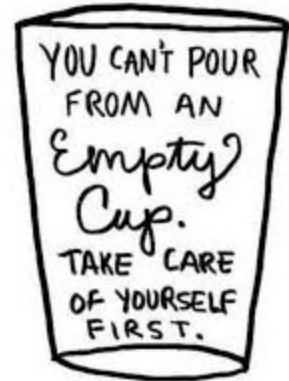


# Don't be afraid....

- Agree how, when and who
- Set clear parameters/objectives for the service
- Do put restrictions on the service – only for flares/IBD medication queries/change in IBD condition
- Operational policy – regularly reviewed and updated to mirror the service provision
- **JOB PLANNING** – crucial in providing the evidence to support your restrictions
- Sign post elsewhere – CCUK, CCUK Flare charts, RCGP Toolkit
- Back up your concerns with fact – sadly managers are not interested in emotions ☹
- Be kind to yourself ☺

# Never feel guilty

- We are only human
- Self preservation is key
- Set boundaries both professional and personal
- Don't compare yourself to others – do what you can with what you have (and don't if you can't!)
- Suspend the service if needs be – agreed with the team and an appropriate timescale and action plan in place
- Stand up for yourself
- There are no rules – create your own to benefit yourself and then think of others



# Empower the patient

- Self management – it doesn't have to be a formal plan, web portal or app
- Patient empowerment
- Clear boundaries
- Relevant information
- Do's and Don'ts of how and when to call for advice
- Clear message – updated according to staffing, demand, skill mix
- Clear communication – written, internet, GP's, social media
- Regularly update the team on what the service demand is and if it isn't sustainable
- Work within your means



**CROHN'S &  
COLITIS UK**



**Inflammatory Bowel Disease  
Tool kit**



GO/2208/2019/UK  
September 2019





# I don't dispute

- That the IBD advice line is invaluable and hugely beneficial
- That we help a huge number of patients day in day out
- That it helps avoid admissions, GP visits, inappropriate prescribing of steroids
- Is cost effective
- Needed
- Wanted
- A life line



# However....

- Change is necessary and has to happen asap
- We can't keep trying to achieve what for some is the impossible
- We have to have clear boundaries in place
- Policies need to be in place to support our practice
- Review of the service has to be done often
- Identifying when its not working and when it needs to be reviewed
- The ability to feel able to sign post elsewhere, put the ownership on the patients where possible and to suspend the service if not fit for purpose



CHANGE



# I ask that this house rules

*That it is time to embrace change and that our IBD advice line services are reviewed, updated in line with its demand and the complexities of managing the IBD patient but with a focus on protecting the well being and sanity of all us hard working, dedicated and passionate IBD nurses.*





THANK YOU  
FOR LISTENING

ANY QUESTIONS ?

NO?  
GREAT!