

Lifestyle issues for Colorectal cancer survivors - perceived needs, beliefs and opportunities

Sarah Porch
Bowel Cancer UK

Professor Annie S. Anderson
Dr Joanne Coyle
Professor Robert Steele



RECOMMENDATIONS

BODY FATNESS

Be as lean as possible within the normal range of body weight

PHYSICAL ACTIVITY

Be physically active as part of everyday life

FOODS AND DRINKS THAT PROMOTE WEIGHT GAIN

Limit consumption of energy-dense foods
Avoid sugary drinks

PLANT FOODS

Eat mostly foods of plant origin

ANIMAL FOODS

Limit intake of red meat and avoid processed meat

ALCOHOLIC DRINKS

Limit alcoholic drinks

PRESERVATION, PROCESSING, PREPARATION

Limit consumption of salt
Avoid mouldy cereals (grains) or pulses (legumes)

DIETARY SUPPLEMENTS

Aim to meet nutritional needs through diet alone

BREASTFEEDING

Mothers to breastfeed; children to be breastfed

CANCER SURVIVORS

Follow the recommendations for cancer prevention

WCRF Global Recommendations

The Panel emphasizes the importance of not smoking and of avoiding exposure to tobacco smoke

Nutrition and Physical Activity
During and After Cancer Treatment:
An American Cancer Society Guide
for Informed Choices

Colorectal cancer: the diagnosis and management of colorectal cancer

The diagnosis and management of colorectal cancer: full guideline DRAFT (August 2011)

5.1 Follow-up after apparently curative resection

of metachronous disease offered a "second chance" at cure. However, it is increasingly recognized that follow-up may have several additional benefits beyond this conventional model, which include: facilitation of audit; characterisation of late-effects of treatment; and health-related opportunities such as early detection of co-morbidities, screening, and delivery of lifestyle advice. The optimal method of follow-up for each of these endpoints may be different. For the purpose of these guidelines, the optimal method will focus on conventional oncological endpoints. However, what should constitute good clinical practice in terms of follow-up has not been established and there is enormous variation in terms of frequency, duration, clinical setting and interventions employed. It is also not clear to what

Background

- Perceived patient **needs** for advice on diet, activity and lifestyle
- Patient **beliefs** about the role of diet, activity and lifestyle
- Patients **interest** in and desire for guidance on diet, activity and lifestyle
- What are the preferred formats, timings and routes of delivery

Participants

Six focus group discussions (FGD) with
Healthy bowel cancer survivors in 6 UK locations

20 men, 20 women

Aged 27 - 84 years

Most retired

41% educated to degree level

Most consumed alcohol within gvt guidelines

Most non –smokers

Mean BMI 26.2 (range 21 to 48 kg/m²)

Mean time from treatment - 18 months

Perceived patient needs for advice on diet, activity and lifestyle to support self management

“...it was a very scary process, eating anything, and actually working out what I could eat, and there was an awful lot that I couldn't eat. And it was very painful eating anything at all... So it was quite terrifying to be honest.” Brenda, FG 4

“What I can eat, right from the very word go when I had ileostomy that was a problem, I had three blockages because of the food I was eating, I found I couldn't eat rice, couldn't eat pasta, potato was my only saviour really to help me feel full up.” Ruth, FG 3

Experiences of dietary advice

*“When I went to the dietician she told me a lot of things that were useful, things that I could eat hot but I couldn’t eat cold, I can eat rice hot, but can’t eat it cold.....In the end she said, you know, you’re going to be the one who makes up your own judge, **it’s suck it and see, or taste it and see, and I’m still on that journey really.**”*

Ruth, FG 3

“I mean prior to surgery it’s low sugar, no salt, fat free, all the rest of it, and then suddenly after surgery it was no, no, you must eat to get your strength back again and build up your weight again, you must reverse all that and drink full fat milk and take plenty of salt, so I was told to do the exact opposite, and, you know, I found that quite difficult.” Ken, FG 1

Conflict, frustration, trial and error... Parameters needed

Beliefs about the role of diet, activity and lifestyle for maintaining health reducing disease risk

“Essentially we have the same diet at home before and after the cancer. I think it’s a sore point with me, ...whenever diet is given as some sort of explanation for bowel cancer, I think it unnecessarily, sort of, stigmatises people...”
Graham, FG 2

“I don't think it [healthy diet] will make any difference personally....I take the view it’s the luck of the draw, you know.I just think it’s almost bad luck really.” Bob, FG 4

Patients views on receiving lifestyle advice

*“some dietary advice would be extremely relevant I would have thought... I basically want **to stack the odds in my favour.**”*

Mark FG 1

Patients views on receiving lifestyle advice

“I think it’s all very well, oh I need to go and exercise, but maybe knowing what it is you should do. Something more specific.”

Janet, FG 2

“It should be reviewed in six months...how are you getting on with your diet, how are you feeling about your programme.”

Ruth, FG 3

Seeking lifestyle information resources and responses

“All you get is American stuff... I would have loved if I could have logged on to a local site that would have given me the kind of information that I’m talking about or let me download a booklet”

Bernadette, FG 1

“I try and buy organic food as best as possible and get a lot of berries and beetroot, certainly more fruit and vegetables and I do feel better for it.”

Fred, FG 2

“Personally what I would like to see at the end of treatment, some sort of survivorship audit where they are looking at your diet, lifestyle, how much exercise you’re getting...if I had more control and felt more empowered about what I was doing and making the right choices I think I could move on a little more sure footedly.” Ruth

FG3

Resources

www.bowelcanceruk.org.uk

0800 8 40 35 40

<http://foodtoglow.wordpress.com/nutrition-and-cancer/eating-well-with-a-colostomy-or-ileostomy/>

<http://cancerhelp.cancerresearchuk.org/>

www.healthtalkonline.org

Emerging issues

- Is giving lifestyle advice something cancer care health professionals should do?
- Are health professionals trained in how to translate the main prevention recommendations into everyday behaviours?
- Can we avoid victim blaming and promote positive opportunities for “stacking the odds in their favour”?

Sarah Porch
Director of Services
Bowel Cancer UK

Sarah.porch@bowelcanceruk.org.uk

020 7386 4001