

Developing a community-based intervention to improve quality of life in people with colorectal cancer: a complex intervention development study.

Appendix A: Results of literature review

Domain	Systematic reviews	RCTs ^a	Other	Summary of evidence
Fatigue	12 [1-12]	29	2	Two systematic reviews of physical activity interventions with cancer patients reported no effect on fatigue. One RCT (n=52) with breast cancer patients reported increased fatigue in the exercise intervention group. Otherwise diet and exercise interventions generally had a beneficial effect on fatigue. Both supervised exercise and home based self directed exercise programmes (normally aerobic but sometimes resistance training) were beneficial. Behavioural interventions to enhance coping and relieve stress also showed a beneficial effect
Pain	3 [11,13,14]	5 [25-28]	1	One systematic review identified 11 studies of self-management education by lay leaders for chronic pain, which show a small but statistically significant reduction in pain (SMD -0.10 (95% CI -0.17 to -0.04)). None of the 11 studies identified included patients with cancer. Three nursing intervention RCTs showed mixed results, two interventions were not focussed on pain as the main outcome and showed no effect, one was focussed on pain and showed a positive effect. A systematic review of behavioural interventions for cancer treatment side-effects concluded that relaxation, suggestion, and distracting imagery can help with treatment related pain management but there were few interventions for the control of prolonged pain. Self management education and nurse led interventions focussing on pain management may be useful in controlling cancer related pain.
General symptoms	6 [1,4,6,11,15,16]	7 [25,28]	3	Mixed evidence for the use of exercise and diet programmes for the improvement of symptoms, positive effect size reported in three systematic reviews (ES=0.35, 0.39 and 0.40), otherwise no significant effect. Positive results from one nursing intervention in patients receiving chemotherapy, but three others showed no effect. Patient education interventions also showed mixed results. Exercise interventions and nursing interventions may be useful for the alleviation of symptoms but the evidence is mixed. Focussing on specific symptoms and targeting those for intervention may be more beneficial than a broad brush approach.
Diarrhoea/bowel problems	2 [16,17]	2 [27,29]	0	Exercise programmes may improve symptoms generally, including diarrhoea. Dietary advice and counselling can help to control diarrhoea. The use of probiotics and fibre may be useful in the prevention and treatment of several diarrhoea syndromes, but there is no evidence of whether these would be useful in the control of diarrhoea related to bowel cancer and its treatment. Exercise and dietary counselling may be useful in the control of bowel cancer related diarrhoea.
Nausea/vomiting	3 [6,8,14]	3	1	Dietary counselling, exercise, and nursing interventions may be useful in ameliorating nausea and vomiting.
Breathlessness	2 [15,18]	3	0	Nurse led interventions (breathlessness rehab techniques and nurse led follow-up) may be successful in helping to reduce severity of, and distress caused by, breathlessness.
Insomnia/sleep problems	2 [6,8]	2	0	One RCT reported a reduction in sleeping problems and one reported non-significant improvements in sleep. Limited evidence to support the use of exercise to improve sleep problems.
Anorexia and cachexia	1 [19]	28	1	Systematic reviews (comprising 28 RCTs) of cancer symptom management interventions, and one small (n=18) pre/post-test study of a telephone based intervention. Review suggests that symptom management of anorexia and cachexia should focus on decreasing energy expenditure or minimising factors creating a negative energy

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				balance, as well as improving food intake. A RCT of a telephone intervention showed no differences in the intervention group as compared with the control group.
Psychological wellbeing	11 [1,4,6,8,11,13-15,20-22]	9	0	<p>Summary: six systematic reviews and 9 RCTs or CCTs of diet and exercise interventions reported positive effects on psychological well-being (including mood, distress, anxiety, depression, esteem and others). Studies of nurse led interventions generally reported positive effects, although one RCT reported no significant difference between intervention and control groups. A systematic review of self-management education reported no significant effect on psychological well-being but small statistically significant effects on self-efficacy. There were a vast number of psychological intervention studies. Due to limited time, I focussed on systematic reviews and meta-analyses. Reported effect sizes for interventions targeting anxiety were 0.36 to 1.99, and for depression 0.19 to 1.2. Two studies could not recommend psychological interventions for depression, one reported a moderate clinical effect in the short term (<8months) using CBT. CBT also has short-term (<8months) effects on anxiety, and longer term benefits are reported for counselling.</p> <p>Exercise and nursing interventions help reduce psychological sequelae, as do some psychological interventions. Group therapy, education, structured and unstructured counselling, and CBT offer most promise over the medium and long term. Targeting those at risk of, or suffering, significant psychological distress may be most beneficial.</p>
Sexual problems	1 [23]	3 [25,27,30]	1	<p>Summary: majority of studies were with prostate cancer patients, one systematic review identified an RCT with cervical cancer patients. No studies of sexual problems specific to colorectal cancer patients were identified. Two nurse led interventions which addressed symptom management, including patient reported sexual dysfunction, were identified. One reported no effect, whilst the other reported a positive effect on sexual function (ES=0.45) and sexual limitations (ES=0.51). The use of sexual aids (eg Viagra, vacuum constrictors etc) can be beneficial in the short term, but long term use by patients is limited. Very few studies on female sexual dysfunction in the literature, one with cervical cancer patients suggests that vaginal lubricants may help. Couple counselling also produced significant improvements in male sexual function in the short term (3 months) but not longer term. Difficult to conclude what type of intervention might be helpful.</p>
Social wellbeing	2 [1,6]	3	1	<p>Summary: very few studies specifically focussed on social well-being, insufficient evidence to make any recommendations.</p>
Physical functioning	11 [1-4,6,7,9,11,13,16,24]	11	0	<p>Generally diet and exercise interventions improved physical functioning (one meta-analysis reported an effect size of 0.52), but not universal (a review of 4 meta-analyses and 2 systematic reviews reported a small or zero effect size). An RCT of a home visit nursing intervention reported no significant group differences, whilst a self-management education intervention reported statistically significant reduction in disability (SMD -0.15).</p>

^a RCTs not included in the systematic reviews were referenced.

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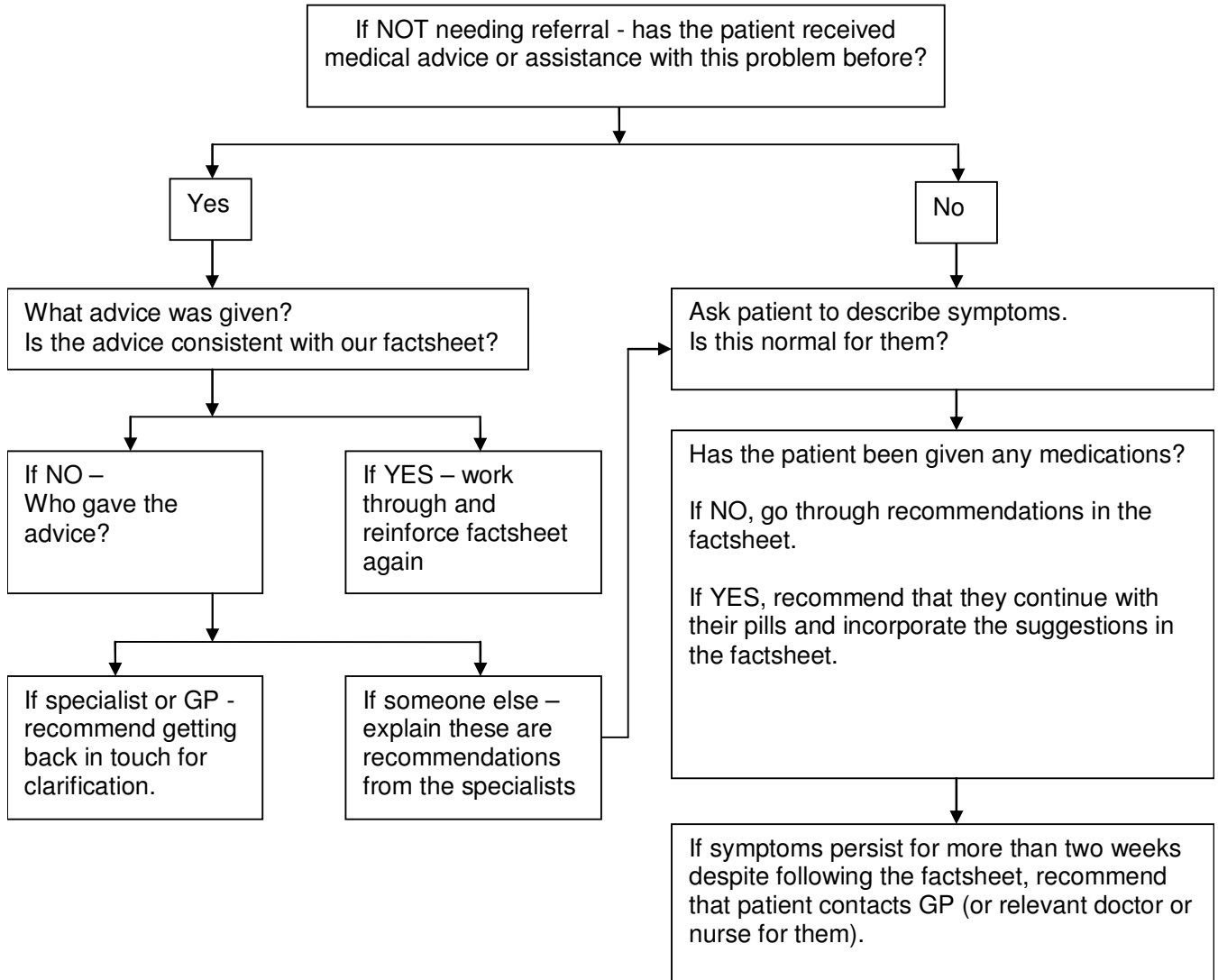
Appendix B

Intervention Prompt Cards

[Each issue will be printed onto a separate card. There will blank cards for the participant to fill out with problems they may have, which are not covered by the pre-printed prompt cards.]

Body	Mood	Activity	Money
diarrhoea	feeling anxious	walking a short or long distance	travel insurance
constipation	worrying about the future	lifting heavy bags	dealing with debt
trouble eating	feeling down	eating, washing, dressing yourself	sick pay or pensions issues
breathlessness	feeling that there is nothing you can do to affect your illness	work or other daily activities	health costs (eg prescriptions, or special equipment)
tiredness	irritability	hobbies	housing costs (eg extra heating costs)
hand and foot problems		family life	travel costs (eg travelling to and from hospital)
pain		socialising with friends	
nausea			
other illnesses			
sexual problems			
sleeplessness			

GENERAL SYMPTOM ALGORITHM



Diarrhoea

This factsheet tells you about:

- Things you can do to help yourself
- Our research
- How diarrhoea may affect you
- Getting help and more information

Things you can do to help yourself

- **Keep a food diary** so you can find out what affects your diarrhoea. Different foods will affect people in different ways.
- **Cut down on your fibre intake** from cereals, fruit and vegetables until the diarrhoea has stopped.
- **Eat** peeled and **cooked fruit and vegetables** instead of raw ones until the diarrhoea has stopped.
- **Avoid milk and dairy products**, such as cheese, until the diarrhoea has stopped.
- **Drink plenty of fluids** to replace the water lost with the diarrhoea.
- **Avoid alcohol, coffee or orange juice.**
- **Avoid fizzy drinks**, which can cause wind and stomach cramps.
- **Eat small, frequent meals** made from **light foods** – white fish, chicken, eggs (well cooked), white bread, pasta or rice.
- **Avoid highly spiced or fatty foods.**
- **Introduce your normal diet gradually.**
- **Eat** your meals **slowly.**
- If the **diarrhoea continues for more than two days, tell your doctor**, who can investigate the cause, and prescribe some anti-diarrhoea medicines for you.
- If you are **worried about your diarrhoea talk to your GP.**
- **Eat live yoghurt but** check with your specialist doctor or nurse before trying this if you are having chemotherapy.
- **Keep a record of your bowel movements** so that you can learn what affects your diarrhoea.
- Take the **anti-diarrhoea medicines** prescribed by your doctor. If your diarrhoea is caused by radiotherapy, changing your diet is unlikely to help.

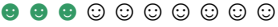
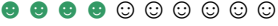

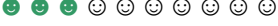
- See your GP or cancer specialist if have diarrhoea 6 or more times in a day, if you are always thirsty, or if you have diarrhoea during the night.

Our research

- Diarrhoea is a very common problem for people who have had treatment for bowel cancer.
- Our research shows that over 4 out of 10 people have diarrhoea at some time.
- The table below shows what people told us, the coloured faces represent the number of people who had diarrhoea at some time.

Time since diagnosis

Question: Have you had diarrhoea?

up to 6 weeks	 3 out of 10 had diarrhoea
6 wks up to 3 months	 4 out of 10 had diarrhoea
3 months to 6 months	 4 out of 10 had diarrhoea
more than 6 months	 3 out of 10 had diarrhoea

- After 6 months **only 1 person in 10** said that they still **had quite a bit of diarrhoea**.

How diarrhoea might affect you

- It can **interfere with travel, working, exercise, going out, and relationships, including sex**.
- It can make people **plan their days around where toilets are**.
- **It can cause stress**. If blood is in the diarrhoea, it can cause even more worry – this is usually nothing to do with cancer but can be checked by your GP, specialist or nurse.
- **Advice about it can be confusing**. Sometimes people contradict one another.
- Sometimes, **it can catch people out**, causing leakage. We have another factsheet on **Uncontrolled Diarrhoea**.

Getting help and more information

More detailed information is available on the Macmillan website at:

<http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Symptomssideeffects/Aboutsymptoms/Commoncancersymptoms.aspx>

Let your GP or nurse know if you are having problems so that help can be arranged.

Much of the information contained in this handout is based on information available on the Macmillan website (<http://www.macmillan.org.uk>) and is copyrighted © Macmillan Cancer Support 2009. We have permission from Macmillan to reproduce this material. Some of the dietary advice is based on that given in the National Cancer Institute booklet “Eating Hints Before, During, and After Cancer Treatment” NIH Publication No. 09-2079 Printed September 2009.



Goals and Action Plans

Setting realistic and challenging but achievable goals and planning how to reach them can help you to develop a sense of control and improve your health and well-being.

We have given some examples below and over the page there are blank goal and action plan forms for you to fill in with your own goals.

GOAL(S):

1. *To improve my fitness so that I can go for a half hour walk with my friends by the end of the month.*
- 2.
- 3.

ACTION PLAN(S)

It is important to be as specific and comprehensive as possible when thinking about how you will achieve your goal. Think about:

- **What** you are going to do
- **Where** you are going to do it
- **When** you are going to do it
- **Who or what** you need to help you do it

My Specific goal

- **What** am I going to do? *Walk for 10 minutes twice day for the next week.*

My Action Plan

- **Where** am I going to do it? *The park, because it isn't too far and the dog would get off the lead **OR** down to the shop to get a paper.*
- **When** am I going to do it? *After breakfast and again after lunch.*
- **Who or what** do I need? *I will take the dog with me to keep me company and I will make sure my wound dressings are safe before I leave.*

These are just examples, you have to decide for yourself what's important to you and how best to achieve your goals. The nurse can help you to do this, but you must make the final decision. Try to start with one or two goals so that you don't feel overwhelmed.



Self-Monitoring Plan

Keeping a record of your day can help you to keep track of how you're getting on and how you feel. **Please complete this diary every day for at least the next seven days.** The nurse will telephone you in about a week to discuss how you have been getting on and it will be very useful to have these diaries with you when you speak to the nurse.

We have given an example of a completed plan below. There are blank forms for you to fill in over the next week or so. It will be very helpful if you can rate how you felt and write down what you were doing before, during and after each event.

What is being monitored: number of minutes walked each day		
When, frequency: twice a day, after my walk		
Date, Time	How I felt 0 = very bad 10 = very good	what was happening? e.g. where; with whom; previous activities
Monday 1 st March 9.30am	10	I'd had my breakfast, then took the dog down to the park. I got a wee bit breathless on the way back but it wasn't too bad. It took me about 15 minutes to walk there and back. Afterwards I put my feet up with a cup of tea and a biscuit and watched a bit of telly.
Monday 1 st March 4.30pm	5	I'd been working in the garden for about an hour potting up some plants, then took the dog down to the shops to get my evening paper. I felt a wee bit breathless on the way down. I really struggled on the way back and had to stop three or four times. It took me about 15 minutes to walk there and back. Afterwards I had to have a lie down.

The more detailed you can make your description of how you were feeling and what you were doing, the better. This will help you to identify if there are certain activities that make you feel better or worse or if there are certain times of the day