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Post-Treatment Information Package for People with Colorectal Cancer: A Collaborative Approach

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On behalf of The Colorectal Cancer Research Group BCCA, Vancouver Island

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Journey for people with colorectal cancers



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Why this project?

- Many stories from our clinical practice that describe the desire for more information at the end of treatment
- Describe a feeling of “being cast adrift” following treatment
- Despite endorsement in the literature, few treatment summary and follow-up information programs exist in practice
- Research about colorectal cancers is limited



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Goals of this Project

- To develop a draft treatment summary and follow-up package for people with colorectal cancer
- To obtain feedback about this information package from people with colorectal cancer as well as health care providers
- To pilot the implementation of the information package



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What is the Information package?

- Record of Care
- Reminders for follow up visits and tests
- Information on side effects
- Considerations for daily living
- Key contacts and resources



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Post-Treatment Side-Effects

Many people who have finished treatment for colorectal cancer may have some lingering side-effects. Some side-effects will decrease quickly and others may take a while to go away. Everyone's experience will be different.

Generally, over time you will likely notice an increase in your energy and physical well-being. Side-effects of nausea or loss of appetite will usually go away within a few weeks but may take longer.

In this information package, there is information on side-effect issues that may be relevant to you such as peripheral neuropathy, "chemo brain", bowel function, fatigue, anxiety, and depression. Please read those sections that are relevant to you to learn more about possible side-effects of treatment and what you might consider to help you manage them. Remember, each person's experience with side-effects will be different.

To Worry or Not to Worry: When to be Concerned

Your follow-up plan recommends regular visits to your family physician within the first five years after treatment has ended. These visits will allow you to deal with any side-effects you are experiencing and will ensure any problems are dealt with.

The first five years following treatment is the time when recurrence risk is highest. While we hope you do not have to deal with a recurrence, it is important for problems to be dealt with promptly, since earlier detection means better outcomes.

It is important to know the types of side-effects that require further investigation should you experience them. As you will learn as you read the following information, each person will experience the side-effects of treatment differently, not everyone will have the same experiences. Some side-effects of treatment will last longer for some people than others. You will learn what is becoming your "new normal."

Throughout this package, we give suggestions to try. Some suggestions may be helpful, others may not be. If you are unsure or have concerns, it is OK to ask your family physician or other health care professional. If anything changes significantly, report it immediately to your family physician or walk-in clinic if you do not have a family physician.

Changes to be aware of and to report to your family physician include:

- blood in your bowel movements
- a new pain that does not go away
- a cough or shortness of breath that is not going away
- loss of appetite and weight loss that remains a problem
- fatigue that is getting worse

Not everyone will experience the same side-effects of treatment. As you try various strategies, you will discover what works for you.

The Process

- Facilitator-led focus groups
- One-on-one discussions with health care providers and people with colorectal cancer
- E-mail feedback
- Urban and rural settings



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Analysis of Results

- All feedback was documented
- Inserted into a qualitative data analysis program and coded
- Analyzed according to themes
 - Value
 - Presentation
 - Content
 - Delivery



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Value

- Criticism of current practice and lack of information at the point of completing treatment
- Package could be valuable throughout the course of their treatment

“ It looks really good! I think it will really help patients and families to have resources like this one.”

“Its obvious that a lot of thought and effort has gone into this. It looks comprehensive and clear.”



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Presentation



- Design of package
- Ordering of information
- Add tabs for easy access
- Add colours
- Space for notes

“ Use colours. All the papers we receive are white.”

“The personal information such as record of care should be at the front of the package.”



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Content

- Word survivor/survivorship
- Provide as much information as possible
- Bowels section
- “New normal”
- Add more suggestions for managing side effects

“If I went to the doctor every time my bowels changed, I would have lived there.”

“Your habits may never get back to what they used to be, but you eventually settle on a new normal.”



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Delivery

- Personalize
- Nurse led
- Flexibility on
 - timing
 - location
 - Media



“ I was given lots of papers but they are just papers. I needed to talk with someone.”

“We need to change the way things are done so we have time to do this, so people feel there is time to ask questions.”



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Now What?

- Incorporated feedback into the draft information package
- Ready for Implementation



Next Steps

- Received \$60,000 from Colon Cancer Canada to pilot the implementation at Vancouver Island Centre as well as Campbell River and Nanaimo
 - Compare outcomes of the pilot with current standard practice
 - Evaluate the operational feasibility and costs



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Pilot Project

- UBC REB approval
- VIHA REB pending
- Recruiting of nurses
- Recruiting of people who have completed treatment
- Education for nurse participants

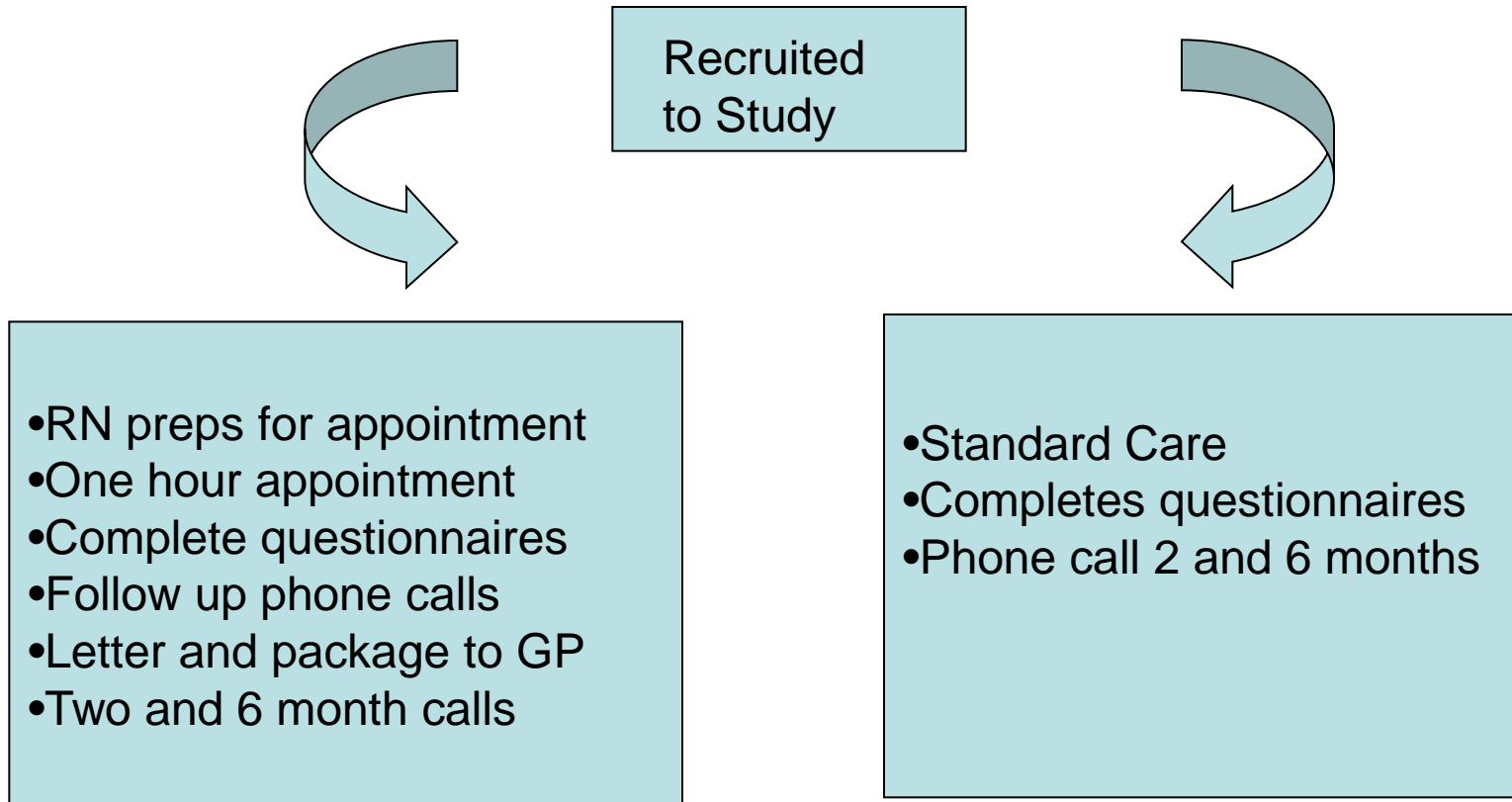


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Two Arms



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Questions?



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