

# UNIT 6

## Relationships

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## Quick Overview

- ❑ For many cancer survivors and their family members, health care providers become an important support and social network. As a cancer survivor transitions to follow-up care, he/she and their family lose this regular support.
- ❑ Partners and family members of cancer survivors may have different expectations of when the person with cancer should be “back to normal”.
- ❑ Family members sometimes tire of extra roles and responsibilities, of ongoing strain, of nothing being “normal”.
- ❑ Some cancer survivors feel pressure to return to their roles as quickly as possible so as to ease the burden of others and give a sense of things being “normal”.
- ❑ Partners and family members may demonstrate overprotective behaviours and may want to hold their loved one back from resuming activities.
- ❑ Cancer survivors who are unpartnered have different challenges. Although many have close family and friends, support is not the same as having a partner. Many single people have concerns and fears around re-entering the dating scene.
- ❑ Same sex couples should have the same opportunity of discussing their couple concerns as others.
- ❑ Cancer survivors have learned through diagnosis and treatment that some family and friends have either pleasantly surprised, or disappointed them in terms of their understanding and support throughout the cancer experience. As cancer survivors move back into social activities and the workplace, they may again experience different reactions from friends, acquaintances, and co-workers.
- ❑ A person can have a partner and many friends and family and still feel very alone during and after an experience like cancer. It is important not to assume that relationships are fulfilling.
- ❑ Many couples who start the cancer journey with a solid relationship and good communication patterns, move into cancer survivorship with the same solid relationship.
- ❑ Couples who start the cancer journey with a poor quality relationship tend to continue having challenges throughout the cancer experience and beyond.
- ❑ Some couples start the cancer journey with a good relationship, but the distress of the diagnosis on one or both can greatly impact the quality of the relationship as they move along the cancer continuum.
- ❑ Fears and concerns about prognosis, recurrence and uncertainty in the future can create emotional distancing within a couple or family.
- ❑ Partners may want to protect each other from the distress (e.g. fears, anxieties) they are feeling so that they do not share their worries with each other. This lack of sharing limits the support they would commonly provide to each other.
- ❑ Physical and body image changes and changes in body functioning can greatly impact a couple’s sexual, intimate, and emotional relationships.

## Introduction

People with cancer, their partners, and families are not necessarily aware of or prepared for the many challenges they can face adjusting to a “new normal”, as they transition from treatment to recovery and cancer survivorship.

As a person completes treatment and begins the transition from active care to recovery to follow-up care, many relationships inevitably change. The cancer survivor and family leave the social network of the health care team who have provided safety and support and an understanding of the cancer experience. The completion of treatment often signifies the expectation that life should return to “normal” when in fact, the road to recovery may take to months to years, and some may not recover. Different expectations about when a person should be ‘back in the swing of things’ creates strain within a family. Many cancer survivors and their partners find that life will never be the same, in some or many aspects. The “new normal” that evolves can bring many relationship challenges to couples, family, friends, co-workers, and those who are unpartnered.

Cancer survivors, their partners and families, need to be prepared for possible new imbalances now that the focus is on recovery, not treatment. They should be aware of the issues of cancer survivorship that they may encounter as many family, friends, and co-workers no longer consider them to be “sick”. Providing this information is part of the role of the nurse. Nurses can assist cancer survivors, their partners, and families to:

- sort out issues that are preventing a smooth adjustment
- help people with their ongoing feelings of distress, fears, intimacy issues
- assist in establishing new and relevant relationships with health professionals and others (i.e. support group)
- assist in examining and attempting to improve the quality of their relationships.

Cancer can change what is meaningful in life. Some cancer survivors experience a shift in values and what is important to them, and change life goals accordingly. For others, cancer becomes the focus of life and their lifework. Others want life to return as much as possible to what it was before diagnosis. When one person experiences a shift in what is meaningful, it usually impacts the partner, family, and other relationships.

## Applying the CANO/ACIO Standards

The CANO/ACIO standards and competencies indicate that the specialized oncology nurse provides follow-up care and continues to explore the changes and challenges. With the transition from active to follow-up care, when immediate side effects have lessened, there is opportunity to help the person with cancer, their partner and family identify changes and challenges to determine what information and assistance they may need.

## **CANO/ACIO Standards and Competencies Relevant to this Section**

In providing care around relationship issues in cancer survivorship, the nurse will be addressing several practice standards and related competencies. The following highlight the standards with some of the most relevant competencies.

### **Practice Standard: Comprehensive Health Assessment:**

Conduct a systematic, comprehensive psychosocial, spiritual, and cultural assessment that includes the individual/family's response to cancer, their main concerns, feelings, fears, goals, and understanding of prognosis. Assess the individual/family's financial, social, and practical concerns that may impact their cancer experience. Explore and document the impact and meaning of illness on the individual/family and their support systems.

### **Practice Standard: Supportive and Therapeutic Relationships:**

Understand the cancer experience and the different needs, feelings, fears, concerns, and losses that the individual/family may encounter as part of the cancer journey. Apply knowledge of family dynamics and disease adaptation to support the individual/family's adjustment to managing and living with the uncertainties of cancer. Assist the individual/family to maintain/establish relationships with individuals or groups who have significant meaning to them over time. Identify individuals and families that require supportive, psychosocial, and spiritual care and refer in a timely manner.

### **Practice Standard: Teaching and Coaching:**

Assess the individual's understanding of common psychological reactions and responses to the cancer experience and providing information about effective coping mechanisms. Identify limitations in the nurses' own skill and knowledge base and referring to others when appropriate. Assisting the individual/family to identify and build on their existing strengths when confronting new information and situations.

### **Practice Standard: Facilitating Continuity of Care/Navigating the System**

Apply knowledge of the individual/family's changing needs as they move across the cancer care continuum, supporting them through the transitions. Initiate, advocate, and mobilize agency and community resources. Apply knowledge of the impact of cancer on the individual/family roles and relationships, facilitating role redefinition, and adaptation. Instruct the individual/family about the appropriate person to contact for concerns and problems. Advise the individual/family concerning survivorship issues and the resources available to support them.

## Literature Review

It is well recognized that the cancer journey not only impacts the person with cancer but also the partner, the couple as a unit, family members, the family unit, friends, the social network, and co-workers. As cancer survivorship is a relatively new concept in oncology, information is lacking on the stressors, resources, meaning, and quality of life reported by survivors and family caregivers and the interrelationship between survivors' and family caregivers' quality of life (Mellon, Northouse & Weiss, 2006, p. 120).

The following selected literature review contains examples of literature and research about relationships. See Unit 8: Psychosocial Health and Well Being for content related to reactions and responses to cancer and treatment. The impact on sexuality of cancer survivors and their partners is discussed in Unit 7: Sexual Health. Cancer survivor's relationships with co-workers are addressed in other sections of this module.

## Health Care Team Relationship

For many people with cancer and their family members, health care providers become an important support and social network through treatment. As a person with cancer transitions to follow-up care, the cancer survivor and their family lose this regular comfortable support (Mitchell, 2006).

## Family Relationship

“Cancer has been described as a family disease (Boyle, 2003b; Moulton, 2000; Rowland et al., 2001). Considered “secondary survivors”, families have unique issues and provocations as they cope with life after cancer (Boyle et al., 2000; Mellon, 2002). Families must integrate and synthesize information often of a secondhand nature, monitor, and supervise ongoing care requirements, and worry in isolation about what the future holds. Guilt may prevail. For example, family members may ask themselves questions such as: Could I have recognized the symptoms earlier?; Should I have forced him to go to the doctor even though he resisted?; or How could I have been so consumed with the kids that I did not see his weight loss? These enduring feelings of guilt can plague families for a long time. Families of cancer survivors experienced feelings of frustration, isolation, confusion, and tiredness in response to the competing demands of providing usual family care in conjunction with the accommodating survivor needs “More in-depth investigation of family issues during survivorship is required because the future portends the addition, rather than the detracting, of care giving expectations that are imposed on families”

(Carroll-Johnson, 2006, p. 37).

Studies with breast cancer survivors have demonstrated that their partners and other family members (e.g. children) can experience a variety of emotional and psychological changes (e.g. anxiety, uncertainty, depression, fear, symptoms of post traumatic stress syndrome, and avoidance) (Segrin, Badger et al. 2007). Some family members report higher levels of distress than that of the cancer survivor. The distress experienced by some breast cancer survivors (e.g. depression, anxiety) impacts on the distress of family members, particularly if the breast cancer survivors' reactions are visible to others. Family members (i.e. daughters) may experience the same or similar symptoms as the person with cancer. (Segrin, Badger et al, 2007).

In a study by Mellon, Northouse & Weiss (2006) cancer survivors and their family caregivers between one and six years post treatment, were interviewed about quality of life, stressors such as fear of recurrence, family stressors, and family hardiness. The results of this study found that, "cancer survivors reported significantly higher quality of life, less fear of cancer recurrence, and more support than their family caregivers. The strongest predictors for cancer survivors' quality of life were family stressors, social support, positive meaning of the illness, and employment status. Whereas the strongest predictors for family caregivers' quality of life were fear of recurrence and social support. Both the survivor's and family caregiver's quality of life independently contributed to the other's quality of life" (Mellon, Northouse & Weiss, 2006, p. 120). The authors reported that some family caregivers may be more susceptible to fear of recurrence because they have had little contact with health professionals and fewer opportunities to ask questions or get information. In their discussion, Mellon, Northouse & Weiss (2006) stress the importance of including family caregivers in the different aspects of cancer care.

Tension and disruption can occur when a cancer survivor is ready to leave the cancer journey behind and the family is not (Australian Government National Health and Medical Research Council, 2003). Family members may be perceived as demonstrating overprotective behaviours, resulting in the cancer survivor feeling resentful. On the other hand, family members may want to get back to some semblance of "normal" and the cancer survivor may not be ready or able to move on (Mitchell, 2006). The cancer survivor may feel frightened, feel anxious, may not want to move on from the cancer experience, or may be reevaluating life priorities. If cancer survivors do not feel that those they feel closest to understand what they need and what they are going through, they may look to those with similar issues and needs for support and understanding. They may seek out other cancer survivors or support groups where they feel understood and accepted. (Australian Government National Health and Medical Research Council, 2003).

Family members do not generally know how to be supportive in discussing cancer or responding to the thoughts, feelings, and behaviors of the person with cancer (Lewis, 2006). During treatment for cancer, the roles, and responsibilities within relationships are often adjusted as the person with cancer may not be able to perform his or her usual functions. With the completion of treatment, some family members want and expect duties to be readjusted immediately, even when the recovering family member is not ready. Others may find that they enjoy new responsibilities and do not want to give up a role they have taken on (Fergan & Gray, 2009).

For partners or family members who are performing care giving duties for their loved one during treatment for cancer, the relationships may change. A variety of challenges including aspects of emotional, psychological, sexual, intimate, and social relationships may be experienced (Segrin, Badger et al, 2007).

## Children's Reactions

Most of the studies examining children's reactions to cancer in the family do not extend past two years of diagnosis. If a parent is diagnosed with cancer, children are often distressed about their parent's health as well as their own sense of security (Lewis, 2006). Some children think more negatively of themselves and have a poorer self-esteem, than their peers with parents not diagnosed with cancer. When a parent experiences cancer, the quality of their parenting may be affected and they may not know how to help their distressed child (Lewis, 2006). A variety of studies examining the emotional and psychological impact of cancer on the person with cancer and family members suggests that adolescent girls may be at increased risk of adjustment issues (Segrin, Badger et al., 2007).

## Couple Relationships

Couples experience many different stressors, changes, and challenges in their relationship during and after cancer treatment. These changes and disruptions range from practical, financial, parenting, and emotional distancing (i.e. avoiding conversations, lack of sharing feelings and fears), to changes in intimacy and sexual activity, mutual support, and planning for the future (Fergus & Gray, 2009; Holmberg et al., 2001; Sormanti & Laysner, 2000).

Many couples adjust well to a diagnosis of cancer and its treatment and may find that the relationship remains close and stable. These couples are able to use their strengths to remain open and honest, to share couple concerns, and to continue to be each other's main support (Badr, Acitelli et al., 2008; Sormanti & Laysner, 2000). Some couples feel they have grown emotionally closer, their relationship has improved, and that they are more intimate (Dorval, Guay et al. 2005; Manne & Badr, 2004).

For other couples experiencing cancer, the relationship becomes strained and emotionally distant. Attempting to protect each from their feelings, fears, and concerns they may avoid or pretend that nothing is wrong. These couples may not engage in the difficult conversations of such topics as prognosis, fears of dying, and living with an uncertain future. Emotional isolation may be experienced as they try to manage their own emotions and the emotions of their partner (Skerrett, 2003, Badr, Acitelli et al., 2008; Fergus & Gray, 2009).

Couple relationships can change because one or both experience emotional and psychological distress. This decreases the quality of their relationship. Some couples blame their break up on the stress of the cancer experience (Badr, Acitelli et al., 2008).

The term 'relationship talk' describes a couple 'talking about the nature and state of one's relationship, what one needs from the relationship and the relationship implications of a shared stressor' (Badr, Acitelli et al., 2008, p 64.) Badr and colleagues (2008) evaluated lung cancer patients and their partners three and six months post treatment and reported that patients and partners who had more relationship talk experienced less distress and greater marital adjustment over time. The more satisfied the person was with the relationship talk, the less distress they experienced. Over time, partners had less distress than patients with more communication about their couple relationship. The work of Badr and colleagues (2008) stressed the need for couple-focused interventions emphasizing communication and relationship needs of both.

Most couples, no matter how high functioning, have been challenged with the demands of cancer and its treatment. Fergus & Gray (2009) describes how 'even high functioning couples may be thrown off course as they struggle to meet the demands of illness amidst the disruption it causes in the relationship' (p. 1113).

Studies have demonstrated that one person's distress can influence those who they are close to. If one partner is anxious, this can contribute to the other partner becoming anxious, even if they are not facing the same threat (Segrin, Badger, et al, 2007). Evidence suggests that levels of psychological distress are similar in both the cancer survivors and their caregivers (Kim, Kashy, et al., 2008). Kim and colleagues (2008) found that "each person's psychological distress is the strongest predictor of their own quality of life, the partner's distress, and the (dis)similarity in distress of the couple also play significant roles in one's quality of life" (p. 203).

The support of a partner is paramount in a cancer survivor's adjustment super ceding other family members' and friends' support (Fergus & Gray, 2009). This provides rationale for the importance of helping a couple to identify stresses and problems within their relationship and to address the issues as a couple. Hodgkinson, Butow, et al., (2007) found that the quality of the couple relationship may greatly impact on the distress and needs of both the cancer survivor and his/her partner.

In a longitudinal study of breast cancer patients and comparison controls that aimed to determine whether a breast cancer diagnosis, personal assertiveness, and partners' relationship focused coping were sources of variation in relationship satisfaction over time it was found that relationship problems were not necessarily dependent on a breast cancer diagnosis. Those who were more assertive about their own needs and who had partners that were focused on maintaining/growing the relationship were more satisfied in both groups. The authors felt that for those who already find it hard to express their feelings and who feel tension when they open up about their emotions, a breast cancer diagnosis may increase the risk of relationship dissatisfaction. Additionally it was recognized that the relationship focused coping of the partner was very important (Hinnen, Hagedoorn, et al, 2008, p. 750).

Partners of cancer survivors provide support to their mate, but they too need support for years after the diagnosis and treatment of cancer (Hodgkinson, Butow, et al., (2007). Anxiety demonstrated by partners of women with breast cancer negatively impacts the breast cancer woman's quality of life (Segrin, Badger, et al, 2007). As there is some evidence to suggest that partners do not always share openly in front of their loved one, conducting an assessment separately may provide more open honest information from the partner. In a study of women with breast cancer, Segrin, Badger, et al, (2007) found that both breast cancer survivors and their partners experienced anxiety while going through treatment. The partner's anxiety influenced the anxiety of the woman with breast cancer. The partner's anxiety was associated with the woman's well-being (e.g., depression, fatigue, and symptoms management). A partner's ability to cope with distress, or get help with their distress benefited both partners in terms of helping partner anxiety and impacting the quality of their relationship (Segrin, Badger, et al, 2007). In a study with cancer survivors and their partners, Hodgkinson, Butow, et al., (2007) reported that "higher distress in partners was correlated with higher distress in survivors and higher need in partners was correlated with higher need in survivors" (p. 412). The reactions of one partner affect the reactions of the other (Dorval, Guay et al 2005).

The quality and satisfaction of a couple's relationship may change over time. One partner (commonly the healthy one), takes on roles and responsibilities of the other and the other partner (the person with cancer), is released of his or her usual duties. The flexibility of 'give and take' may no longer be available, adding pressure to the healthy partner. This division is commonly not easy for either (Kuijjer, Buunk, et al 2004). With completion of cancer treatment, the healthy partner may be ready and waiting for the recovering partner to begin taking over some responsibilities. The recovering partner may not yet feel ready. This can cause ongoing tension (Fergus & Gray, 2009; Kuijjer, Buunk, et al 2004).

Cancer and cancer treatment can cause changes in sexual functioning, body image, and a couple's sexual routine. The changes can greatly impact a couple's emotional, intimate, and sexual relationship, causing frustration and dissatisfaction for both. These difficulties or changes in sexual performance can affect feelings of intimacy and confidence. They can impact emotional closeness which can cause strain, tension, and resentment within the relationship (Fergus & Gray, 2009; Holmberg, Scott et al, 2001). See Unit 7: Sexual Health for further information.

## Being Unpartnered

Holmberg, Scott et al, (2001) found that single women were angrier, sad, and hurt related to their experience of cancer. These findings suggest that unpartnered women may face more difficulty than those of partnered women.

People with cancer who do not have a partner may have different or more complex issues than those with a partner. The timing of when to tell a potential partner of the cancer, and when to show them body changes are issues (Holmberg, Scott et al, 2001). Body image and self-esteem changes impact initiating a relationship. Some people with cancer feel that the cancer labels them, and that changes to their bodies may limit their chances of having new sexual relationships. (Australian Government National Health and Medical Research Council, 2003).

## Facilitating a Comprehensive Assessment

As the transition to recovery and cancer survivorship becomes imminent, it is important for the nurse to explore and discuss the following with cancer survivors, partners, and families:

- different challenges that they may face;
- different ways to remain open and honest with each other;
- ways to maintain respect for each other's thoughts and feelings; and
- the identification of resources that are available to them now, and in the future.

The nurse can normalize that many couples and families need assistance in adjusting once cancer treatment is complete. It is important for the nurse to prepare the person with cancer, their partner, and family members for the upcoming change in their relationships with the cancer care team. This is often a big adjustment and a sense of loss for cancer survivor and their family.

### Suggested Opening Statement and Questions:

- "For many people, the diagnosis and treatment of cancer changes the relationships with their partner, family members, friends, or co-workers. Some relationships are better, some are more challenging. How have things been for you?"
- "What types of changes have you experienced?"
- "How do you think things will change now that you have completed treatment?"

### Questions to ask the cancer survivor:

- How are you finding things with family members / friends / your partner?
- Who do you lean on for support?
- Do you find that some people treat you differently? How upsetting is this for you?
- Sometimes when cancer treatment is over, some family members are anxious for everything to get "back to normal". Many people who have had cancer say that the old normal is just not possible. What has your experience been like?

### Questions to ask the cancer survivor, couple and family:

- How have things changed for you as a couple (within your family) through all of this?
- In what ways has cancer brought you closer together? In what ways has it pushed you apart?

- Are you the type of family that usually shares feelings with each other?
- What are members of your family saying or doing that are helpful? Not helpful?
- Sometimes, the whole experience of cancer has caused strain and tension within the family. How is your family doing?
- Do you or anyone in your family have questions about your cancer and the future (risk of it coming back, worries about you dying)?
- Having a family meet with a health care provider to ask some general questions can sometimes help open up a discussion within the family. Would a family meeting be helpful in your family's situation?
- After the experience of cancer, some people want to put the experience behind them and move on, close the cancer chapter of their life. For others, cancer continues to be a big focus in their lives, not something that they want to move past. Where would you say you fit in this? Where would you say your partner/family fits with this? In what ways does this difference in your thinking cause any problems or tension?

### Questions to ask a Couple

- Would you say you were emotionally close before all this started? How about now?
- Many couples need some help talking about certain things. Would you like to see someone who may be able to help you open up more to each other?
- How did you show affection for each other before your experience with cancer (hugging, cuddling, holding hands) Has this changed? Why do you think this has changed? Do you miss being affectionate?
- How comfortable are you talking about changes in your appearance, how your body works, and how that affects things sexually?
- How much of a concern are these changes for both of you? How much have you talked to each other about these changes?
- How would you like to see your relationship improve?
- Many couples find that they need some help reconnecting after treatment. Would you like to see someone?

### Questions to ask the partner of the cancer survivor

- How openly can you talk with your partner about changes, fears, and concerns in your relationship?
- What kind of care taking, if any did you provide for your partner when s/he was having cancer treatment? What was that like for you? How has doing that care taking for him/her changed your relationship?
- In what ways does your partner look different now? How this change affected how you feel about him/her?

## Questions to ask an unpartnered cancer survivor

- We know that often, individuals who do not have a steady partner have different concerns and issues than people with a steady partner. How are you finding things?
- Who do you rely on for support?
- What concerns do you have as a single person?
- Some of the big concerns that have been identified for single people are concerns such as:
  - When should I consider dating?
  - When do I tell a potential partner I had cancer?
  - How will they react to my body?
  - Will I totally scare them off?
  - How will the sex part work?
  - Have you been thinking about any of these things?

## Priority Content for Patient Teaching

- Couple/family relationships may change with the completion of cancer treatment. Sometimes responses of family members/partners are supportive and comforting, sometimes not. Some family members don't know how to react, what to do, or what to say to the cancer survivor, and need guidance.
- Recovery is usually slower than everyone wants it to be. Some family members will expect a return to a "normal" routine right after completion of cancer treatment, others may demonstrate protective behaviours for a long time.
- The experience of cancer impacts everyone differently. For some people, having cancer changes them as a person. It changes their values, their outlook on life and what is important, what they want in a relationship. These changes can create changes in relationships.
- Some cancer survivors find that it is the people around them who change. Their partner / family members / friends change what they talk to them about, and how they are included. Sometimes these changes create tension or strain. Sometimes relationships don't survive these changes.
- Everyone deals with cancer in their family in their own way, and it can be well into recovery before loved ones really begin to treat the cancer survivor as 'normal' or they can begin to plan for the future.
- If family members or friends have not been able to support the cancer survivor through their illness as they may have wanted, they experience feelings of guilt or worry about reconnecting (now that treatment is over and everything appears back to "normal"). Ironically, it is the cancer survivor who may put others at ease, to make the first move at reconnecting the relationship.

## Couples

- As the cancer journey moves into cancer survivorship, many couples find that they haven't spent a lot of time on their relationship. They haven't talk to each other about what they are scared of, how they have felt, how they are feeling, and plans for the future. If a couple hasn't been able to be affectionate, to cuddle, to share intimate moments, it can take some time to get back on track with their relationship. Some couples need help reconnecting in certain ways.
- If a cancer survivor or their partner is finding it hard to adjust to physical, sexual, intimate, emotional, or body changes, it is important that they not wait long before seeking help. Changes and challenges need to be addressed sooner rather than later; relationships may diminish in quality over time with feelings of anger, resentment, and bitterness. Don't put off getting help for your patient.
- If one partner continues to experience distress into cancer survivorship (related to fears, worries, uncertainty) it inevitably impacts upon the distress of the other person in the relationship and the quality of the relationship.
- Some types of cancer and cancer treatment result in bodily changes that impact upon the spontaneity and satisfaction with intimacy, and sexual activity. Finding a compromise can often take motivation and frank discussion. Often a health care provider can provide useful guidance and suggestions.
- Often, as cancer treatment comes to an end, partners are excited to move on, leave the illness behind, and "get back to normal". The cancer survivor may not be in the same space. They may feel anxious that cancer treatment has stopped. They may not feel ready to move on and may be still in the cancer frame of mind. Couples often need some help working on this imbalance.

## Being Unpartnered

- Being single can be very difficult through cancer treatment and cancer survivorship.
- Supportive friends can be wonderful but are not the same as having a steady partner

## Counseling

- Many people find that they benefit from some professional help as they move to a new normal after cancer. Some people may find that a non-partial listener helps them sort out changes in their relationships. Very often, couples or families need help to start talking, or they need help keeping the conversation going. Some couples or families may need specific guidance in addressing their issues. Some people benefit from learning the right questions to ask. Some couples require assistance in learning about how to express themselves or how to work things out.

## Examples of Nursing Interventions

- Along with the cancer survivor, many family members need ongoing reassurance that frequent ongoing monitoring of the cancer survivor's situation is no longer needed. Feelings of 'being abandoned' by the health care team can be normalized. The nurse can provide specific directions on who to call for what concerns as they are being transitioned from the cancer care program to cancer survivorship.
- It is helpful to provide opportunities for partners and family members to ask questions and discuss "hard conversations" (e.g. fear of recurrence, prognosis, worries about dying) when the family is all together.
- Normalize how difficult moving forward from the cancer experience can be for the cancer survivor, their partner, and family members with the many changes and challenges. Explain that couples/families may benefit from professional help with being open and honest with each other and knowing how to address all the changes that have occurred (in their relationships, family life, feelings, and fears), and how to now move forward.
- Encourage family members not to demonstrate protective behaviours towards the cancer survivor related to discussions of normal daily life. It is helpful for the partner/family to understand that the cancer survivor needs to be involved with the ups and downs of family life; it helps them to integrate back into everyday living.
- When the cancer survivor is ready to begin resuming normal activities, talk about it as a couple/family so that everyone is aware of the plan.
- Encourage family members to talk about what they are feeling and discuss concerns as their loved one transitions from the sick role.
- For some family members, they can hardly wait to give back certain responsibilities that they have taken on throughout the illness. They may want to give them back too soon, or all at once. Explain that recovery is gradual, that everything cannot get back to normal all at once.
- For other family members, it is hard for them to give up the extra responsibilities. Assist family members in understanding the reasons behind the cancer survivor needing to gradually participate in family life as before.
- When the cancer survivor continues to live with limitations or consequences of the cancer or treatment, help the family sort out roles and responsibilities or link the family with someone who can guide them.

### Relationship with Partner

- Normalize that some couples need time to get to know each other again when the couple no longer has to have the cancer as a focus of their lives.
- Normalize that many couples benefit from professional help to reconnect emotionally, intimately, and sexually.

- Normalize that the cancer journey commonly changes both the cancer survivor and their partner, by creating new or different feelings, new and different ideas, and sometimes different values and beliefs. Inform the couple that as they move into cancer survivorship, there will be less and less focus on the cancer experience. Explore where their relationship is, what feelings each of them have, in what ways things changed in terms of how they are communicating and what they are sharing with each other.
- Consider seeing the couple separately and together. When separate, ask each how they feel the other is doing, and if they have any concerns about well-being. Ask about changes they are experiencing in their couple relationship. With the partner, ask about changes of feelings due to changes in appearance and body functioning, and if anything has changed because of being in the care giving role. With the cancer survivor away from their partner, it gives them an opportunity to share information and concerns about their body image changes that they feel uncomfortable sharing when their partner is present.
- Explore how the cancer survivor is feeling about their body, their self confidence, and how this impacts their relationship with their partner.
- Normalize changes a cancer survivor may be feeling (e.g. feeling less sexually attractive; less interested in sexual activity; less sexually aroused; less of a woman or man).

## Being Unpartnered

- Normalize and acknowledge the unique challenges of trying to find a new partner. When do they tell a potential partner? How much of their story do they tell? When do they show them the changes in their body? Should they tell the person as soon as they meet, or wait until they know there may be something to the relationship?
- Provide detailed information about psychosocial resources that are available.

## Resources

- Encourage your agency to maintain a list of counselors (public and private) who can address different issues.
- If couple/family counselors are not available in your area, provide written material of and accessible relevant written materials. These materials will not replace a counselor, but they may help normalize and validate a cancer survivor's or couple's experience and may facilitate discussion. Some people like to have resources to read and research.

## Learning Activity:

C.R., 46, completed her cancer treatment 6 weeks ago and is in for her first follow-up visit. Her husband F.R. is with her. To date, her visits have focused on the discussion and management of physical side effects. With many of these now resolving, you observe today that she has been able to move her focus away from physical symptoms and describe how her cancer journey has impacted her psychologically. You describe some of the emotional changes she may experience as she moves from being a cancer patient to being a cancer survivor. She asks what else she may need to know as she shifts to what she is calling a 'survivor state of mind'.

Realizing you have limited time remaining in the clinic visit, what information do you think may be important to introduce to C.R. and F.R. to help normalize some of the challenges they may experience as a couple and family?

- Partner and family members may all have different expectations of how a survivor moves from 'being sick' or 'being a patient' to getting back into normal life.
- Some may expect the survivor to be completely back to normal and to move along now as if nothing has changed. Some may be overprotective and some partners and family members may believe that all their lives have changed forever and nothing will ever be the same.
- Explain to family that recovery may take weeks to months with gradual improvement. Acknowledge that this gradual recovery have be hard or frustrating for everyone, especially as everyone is eager for things to get back to some kind of normal.
- If the survivor's cancer has not been openly discussed (follow-up, risk of recurrence, changes in how survivor looks) and spoken or unspoken worries about 'are you going to die? ' have not been addressed, this can cause strain, tension, uncertainty, worries, and the inability to have open honest communication within a family members. The impact can seep into different aspects of life. This can be a hard discussion and survivors may need help from a health care provider with planning or wording of such a discussion. Adults and children tend to cope better when they are informed.
- Reassure family members that 'if anything changes from what I have told you, I will let you know'.
- Different couples/families can experience different stresses, stains and challenges in their relationships and in home life as the person who has had cancer moves back into their normal life. Some couples and families talk about what is distressing them and are able to resolve issues. For other couples and families, stress, resentment, and anger can build and people remain silent. If couples and families are feeling stressed, things are not getting better and people are unable to talk, get help. Suggest resources.
- It is important for couples to talk to each other about their fears around the future, fear of dying, changes in appearance, bodily changes, other changes, and other worries. Lack of openness about these issues can cause ongoing strain and stress and can impact the couple's sexual, intimate, and emotional relationship. May need professional help to start talking, to keep talking, or both. Discuss available resources in cancer program.

- Discuss the different psychosocial resources available in cancer program, different written resources, and the types of health professional they may seek out in their own community. Normalize the need for these services by clarifying that resources are available because of the many different challenges survivorship can create in relationships and many cancer survivors and their partners seek such support.
- For survivors who are unpartnered there are different challenges. It is always important to seek out additional support from the supportive care team which may include psychologists and social workers who can help craft a meaningful care plan for unpartnered patients.

## Selected Resources

### For Nurses

American Psychosocial Oncology Society. [www.apos-society.org](http://www.apos-society.org). *Psychosocial Aspects of Cancer Survivorship*.

Australian Government National Health and Medical Research Council.(2003) *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer*. [www.nhmrc.gov.au/publications/synopses/cp90syn.htm](http://www.nhmrc.gov.au/publications/synopses/cp90syn.htm) (able to print off sections of the manual as needed).

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## For Cancer Survivors , Partners and Families

MacMillan Cancer Support <http://www.macmillan.org.uk/Cancerinformation/Cancerinformation.aspx> Living with and After Cancer Relationships and Communication Life after Cancer.

[www.cancerhelp.org](http://www.cancerhelp.org) Patient Information Coping with Emotions

National Cancer Institute. ([www.cancer.gov](http://www.cancer.gov)) *Cancer Topics Coping with Cancer Managing Emotional Effects, For Caregivers, Family & Friends, Survivorship—Living with and beyond Cancer.*

Cancer Council of New South Wales [www.cancercouncil.com.au](http://www.cancercouncil.com.au) *Patients, Families, Friends Booklets and online information Living Well After Cancer.* Sections: Communicating with Family and Friends.

University of Texas, MD Anderson Cancer Center. ([www.mdanderson.org/patient-and-cancer-information/index.html](http://www.mdanderson.org/patient-and-cancer-information/index.html)) *Patient and Cancer Information Cancer Survivorship Health and Well-Being After Cancer.* On line information to read but on that page you can also print off or read from a booklet called Survivorship: Living with, Through and Beyond Cancer(see Psychological, social, emotional, and spiritual impacts of cancer).

National Coalition for Cancer Survivorship ([www.canceradvocacy.org](http://www.canceradvocacy.org)) Find a Resource Cancer Survivor Toolkit Special Topics Living beyond Cancer including; Intimacy, Family Communication, Emotional Aspects of Cancer (audio or written presentation).

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