THE 2000 SCHERING LECTURE

“Is my mom going to die?” Answering children’s questions when a family member has cancer

By Carole Robinson and Karen Janes

A prescription is needed for helping the family in ways that restore their wholeness and vitality as well as minimize illness-related distress. It is interesting that a mother who is diagnosed with a fractured femur has a rehabilitation program recommended to her. There is nothing comparable for families and children dealing with breast cancer. Nothing. Nothing is not good enough (Lewis et al., 2000, p. 217).

Life-threatening illness is a family affair - this is **not** new news. While only one person has the disease, every family member has illness (Kleinman, 1988). That is, every family member experiences living with sickness. Chronic sickness becomes an unwelcome, intrusive, and disruptive family member who vies for attention and dominance (Robinson, 1998). Cancer comes out of the blue and strikes like lightning, changing the pattern of family life. It is often an invitation to repattern living with surviving. Life is what we want to serve, not simply surviving.

Lewis and colleagues (2000) challenge us to consider that it is not good enough to do nothing to assist families with cancer with the repatterning process. Why not? Some might argue that we are in the most important business of saving lives. When time is extremely precious, why should we spend it on families who are struggling to respond to cancer and to reshape their lives? The short answer is because it matters to both family and individual health. Parents who have cancer worry about their children. Worry takes energy. Worry changes body chemistry. Worry shuts out joy. We invite you to think of helping parents help their children as symptom management that serves life by nurturing both family and individual strengths for dealing with adversity.

Lewis’ program of research shows us that, most often, children live in the shadow of illness. In truth, we have treated the children and adolescents of parents with cancer with benign neglect (Lewis, 1997). This is most true of the intense beginning phase of diagnosis and treatment, when patterns of how cancer will be dealt with in the family are established. We know that how the adults in a family manage the illness sets the pattern for how children manage. (Pay attention here). This means that it is important for the pattern to include the children early in the process. However, health care professionals do not tend to move the children out of the shadows and into active involvement. Interestingly, when offered the opportunity,

neither do parents (Lewis et al., 2000). The focus, sharpened by fear and need, remains on the sick parent and on the marriage.

According to Lewis and her colleagues, “health providers need to generate a prescription for healing the family” (2000, p. 217). Why a prescription? A prescription formally acknowledges the problem while it gives direction for practice. A prescription answers the question of what can be done about the problem with clear specifics about action, timing, and responsibilities. However, given the uniqueness of each family and every child, a single prescription is unlikely to assist healing. Therefore, what we offer are ideas about the problem as seen through a child’s eyes, and an approach that we have found helpful.

Healing is movement towards wholeness (Remen, 1996). Remen believes that humans naturally move towards wholeness; however, often this movement involves a paradox. That is, as life challenges us, we must let some things go in order to become more of who we truly are. This is the case for families as well as individuals. Healing involves remembering, it involves drawing forth the essential and perhaps even simple pattern that captures the integrity of a particular family. Healing requires that everyone be in the picture. When a parent has cancer, healing requires that cancer be only part of the picture.

We think of life as a work of art - a story expressed through colour, shape, texture, and pattern. Within this frame, you might consider life as a quilt that gets pieced together as it is lived. It is a work in progress. Family life has an inherent reciprocity in that family life influences family members and family members influence family life. Cancer moves into the family as an unwelcome, uninvited house guest and takes up residence as a family member. When this happens, the quilt often becomes a crazy quilt. The pattern, colours, and texture become unpredictable; yet, when stitched together they can be amazingly beautiful. Over time, a new pattern emerges. Children’s questions, worries, and fears can be seen as stitches in the quilt as they offer opportunities for connection and reconnection.

The world of children is experientially based. Children make meaning of their experiences and their world in how things affect them and how they affect the world. The focus here is on school-aged children whom Erikson (1963) described as being in the developmental stage of accomplishment. School-aged children work hard at achieving a sense of personal and interpersonal competence by starting things and working through them to a completion that is satisfying. These children are eager to learn and grow through involvement in activities that they find meaningful. They are moving out into the world of interpersonal relationships and thus, are stretching beyond the sphere of family influence (Combrinck-Graham, 1990). School-aged children gain great satisfaction from independent behaviour in exploring and manipulating their environment and from interaction with friends.

What happens when life-threatening parental illness becomes a child’s daily companion? Changed routines and changes in parental support, accompanied by experiences of secrets, worries, anger, and uncertainty, influence their ability to initiate work, learn new knowledge and skills, concentrate, and move through activities to completion with a sense of accomplishment and achievement. For school-aged children, think about how cancer gets in the way of achievements. It can be as simple as not having a ride to soccer practice.

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Before moving on to address children's questions, it is important to consider two myths (adapted from Lewis et al., 2000) that can negatively influence a parent's ability to respond to their children's questions when the parent has cancer.

Myth One: Parents are concerned about the impact of cancer on their children so they address their questions

Yes, parents are concerned. However, this does not mean that they are aware of their children's concerns nor are they likely to feel able to address the concerns. Sometimes parents are simply overwhelmed by their own illness problems. We imagine that many of you have already had an internal conversation about what you as a health care professional could possibly do about the children - parents often think the same way. We mirror each other's worries and fears. When asked, many parents do not know what their children's questions and concerns are. Parents' silence is nurtured by the belief that cancer and the responses to cancer can be hidden; that somehow the adults in the family can go through the experience while at the same time shielding the children. This belief is a particularly hazardous trap for mothers. The lesson here is that parents are as afraid of hard questions and as afraid of upsetting the apple cart of emotions as we are.

The research of Shands, Lewis, and Zahlis (2000) informs us that when mothers talked with their children about the mother's breast cancer, there was a tendency to focus on cognition and medical facts rather than the children's feelings, worries, and concerns. As well, talk about how the cancer may affect the child's life was absent. Thus, these authors comment, "mothers in this study could have benefited from written materials that described how young children, at different developmental stages, hear and process what they are told" (p. 84). They need help knowing the kind and amount of information that is helpful to their children.

Myth Two: Questions require answers

Another belief that gets in the way is that "questions require answers." Underneath that belief is one that says "and I need to have the answer." These are problematic beliefs because they generate fear about entertaining and inviting questions. The thinking goes, "If I ask or invite a question and do not have the answer or cannot fix the problem, then I am a failure." Again, think about questions as stitches in the quilt of family life - threads that bring us closer together in our understanding and appreciation of each other. I'm sure you have all had the experience of listening to a young child ask what seems like endless questions such as, "Mummy, why is the sky blue?" "Why do the clouds move?" "How do they stay up in the sky?" "What makes wind?" We patiently and explicitly try to answer the questions, only to find that the answers were not attended to - "But Mummy, why is the sky blue?" Often it is the listening and connection and our attention that is important. Questions engage us in relationship. They are not necessarily a request for an answer. Interestingly, answers, particularly those we think of as being "the" answer, end conversations.

So, we think of questions as stitches, as signposts that guide us to the heart of worries and concerns, stones to be turned over to see what is underneath. Depending on the child, the questions can be asked in words or actions or even silence. Questions are best addressed in words so, in the most helpful of worlds, it will be the loving adults in a child's life who will, early in the cancer experience, anticipate and draw forth the questions in words. This is no small request. At a time when parents are stretched as thin as parchment, we ask them to do more - to take care of their children.

These are the guidelines we recommend for parents: begin the conversation early in the journey; plan the conversation in advance (you might even want to practise it); do it all together; keep it as simple as possible; focus on what the children's lives will look and

feel like; let them know how to be helpful; anticipate questions; assure them that the conversation will continue; and, listen carefully to appreciate the children's experience (Hamilton, 1999). Now, on to specifics about children's questions.

What are the questions children have in response to cancer's presence in the family? School-aged children have a wonderful curiosity about life and living, and a zest for interesting details. During this so-called latency age, children have both concrete and abstract concerns about illness, particularly serious illness. And make no mistake, in this media savvy age, children know that cancer is a serious illness. Cancer is bad news. It's nasty, man. It kills people. There are many questions children have - spoken and unspoken. These questions give us access to their experience of life and cancer. Their questions relate to three fundamental needs: satisfaction of their basic physical and emotional needs, an understanding on their level of what is happening, and reassurance that they will be cared for no matter what happens (Harpham, 1997a). Questions children ask centre on three themes: questions about cancer, questions about treatment for cancer, and questions about life with cancer - and life after cancer.

Questions about cancer

Children ask, "What does cancer look like?" Perhaps an unspoken question is, "How will I see cancer in my mom or my dad?" Children ask, "What causes cancer? What makes a cell go crazy?" The unspoken questions: "Why did this happen to my mom or dad? Who or what is responsible? Why my mom, my family - why me? Did I cause the cancer? Could this happen to other people in my family? Could this happen to me some day? Is cancer 'catching' or contagious? Is there any way to stop cancer?" Listening to the spoken and unspoken questions about cancer causation gives us opportunities to find out children's theories, to correct misconceptions, and to reinforce positive health choices. Children need to know that they can't "catch" their parent's cancer, and no one else can either. Some adults worry about cancer's possible contagion, so it's no surprise that children worry about this too. Older school-aged children are asking more frequently about hereditary aspects of cancer. It is very important to reinforce that nothing they have done has caused the development of their parent's cancer, especially if they hear that stress causes cancer. What child has not caused their parents stress? Children can be overwhelmed by feelings of guilt for a situation totally outside their control (McCue & Bonn, 1994).

Children ask, "How can doctors tell if a person has cancer?" They are interested in the process of discovery, but perhaps they are also asking, "Could there be some mistake? Are you sure my mom or dad has cancer?" Fascination with numbers and statistics leads to questions about cancer's incidence and prevalence - wondering how big a problem cancer is. Some children ask, "Do more people die from cancer than live?" Perhaps the unspoken questions are, "What can I hope for?" and the biggest question of all: "Is my mom or dad going to die?" In their book for parents, McCue and Bonn (1994) remind parents gently but firmly: "Faced with the news of a parent's grave illness, all but the youngest children are going to wonder: Will you die?" (p. 18).

Questions about cancer treatment

Given the intricacies and complexity of cancer treatment, it is not surprising that children have many questions about both the science and the experience of treatment. Here are just a few, "How does the chemo kill cancer cells?" "How does radiation treatment kill cancer cells?" "Can't radiation give you cancer?" "Are you radioactive when you have radiation?" "Why do some people get radiation and other people get chemo?" "Which is better?" "What is a bone marrow transplant?" "How many bones do you put marrow in?" "How does it get to the right place?" "When does the person start to look like the person who gave them their bone marrow?" "Why does chemo make people bald?" "Why is my mom or dad tired all the time?"

Children are concerned about the safety and effectiveness of cancer treatment. If children are unable to obtain direct answers to questions (spoken or unspoken), they use their imagination and creativity to invent explanations or rationales, which can be much more frightening than the truth. Children are very interested in not only how the treatments work and what they will do to their parent as well as to their parent's cancer, but are keen to find out whether the treatment will be successful. With great courage they may speak the unspoken question, "What happens if the treatment doesn't work?" Children have inquiring minds, and inquiring minds look for answers. The challenge is to hear the spoken and unspoken questions and to anticipate children's concerns. Issues of truth, honesty, and hope direct the stitches of questions for children, parents, and professionals. McCue and Bonn (1994) offer this comment about honesty and truth, "being honest does not mean telling everything....What it does mean, simply, is never telling anything but the truth" (p. 10). Children are helped by explanations about what is wrong and by naming the illness - cancer. Introduce children to some of the language they will hear - if they haven't already. They need to know what can be done to help, and the caring adult's best understanding of what may happen. They are also helped by knowing their parents and family will do everything they can to help mom or dad get better, and to care for the needs of the children.

Questions about life and living

Children are full of life. They teach us that living is different than surviving. Children know about being healthy and sick at the same time. Through play they bring what is right into the foreground rather than letting what is wrong dominate the picture. What kinds of questions do children have about life?

What's happening to me? When the body asks questions

Sometimes when children cannot ask questions in words, their bodies will do it for them. Sometimes, like voiced questions, body hurts are a request for loving connection. "Mummy my stomach hurts. Do I have to go to school?" "I can't sleep. I had a bad dream. Can I come to bed with you?" "My head hurts. Will you come and get me?" "I feel sick. Do I have cancer too?"

Often children's worries, confusion, and uncertainty are expressed as body pain. Children respond to difficult situations like a parent's diagnosis of cancer in the same ways they respond to other life difficulties; however, the pattern will likely be exaggerated.

What is needed? Firstly, an appreciation of the particular child's unique tendencies. I often ask the question, "Is Elizabeth the kind of child who gets a sore tummy when bad things happen or does she cry or withdraw?" Secondly, we need sharp eyes and ears to see the pattern. Perhaps this may even require a group effort through involving other important adults such as teachers. Thirdly, when physical hurts are involved, then physical problems need to be ruled out. Finally, once a physical problem is ruled out, work with the metaphor. Some questions that we have found useful include, "If your tummy ache could talk, what would it say?" or "What is the colour of your headache - is it a mad colour? a sad colour? a scared colour?" or "Will you draw me a picture of your headache?"

How does grief feel? Moving close to the bone

Life-threatening illness brings loss, and grief is the response to loss. For children whose parent has cancer, there are real and significant losses, which might include: loss of routine, loss of favourite foods, loss of laughter, loss of the presence of both the sick and the healthy parent, and loss of family time. Such losses can add up to loss of stable ground and of security.

The literature talks about anticipatory grief as if the only grief that matters is that which occurs in anticipation of death. This does a great disservice to the grief associated with life-threatening illness by diminishing and even dismissing real and present losses of the

moment. Further, when health care professionals conceptualize grief as a response to the anticipation of death, our ability to be helpful is diminished as we do not pay attention to the losses of the moment. The important message here is to pay attention to current losses.

Children's expressions of grief are tricky. Being full of life, they do not tend to dwell in grief but can move quickly between the sun and the shadow. They, too, do not want to upset the emotional apple cart, so they may hold their grief tight. Again, it is important to watch for patterns, which can be aided by a sense of the family's way with showing grief. Grief can have different faces: sadness, anger, withdrawal, rebellion, or overwhelming worry. Children who are grieving may seem to move backwards toward a younger, smaller time. They may seek the comfort and companionship of animals or favourite stuffies. In our experience, young school-aged children often can talk more easily about the sadness that a favourite stuffy or a pet is feeling than what they find in themselves.

It is helpful for children to have their losses recognized and their feelings acknowledged. Harpham (1997b) has offered a creative way of doing this with her children's book "Becky and the worry cup."

When will things get back to normal?

Balancing hope and honesty

We have talked of the loss of "normal" life that occurs with life-threatening illness. Things become unpredictable as the usual patterns of life shift and sometimes shatter. Children and grown-ups try hard to hang on or to go back to life as it was before. Letting go and moving on to a new normal is difficult. However, simply incorporating cancer in the fabric of family life creates a new pattern. The challenge is to see and then recognize the new pattern, to find ways to trust the new pattern, and to find comfort in the new pattern. The interesting thing about the new pattern is that it is very seldom all new. It includes pieces of the old. We can help children find comfort by paying attention to what they would like to keep or regain from the old pattern and by highlighting what works in the new pattern. In particular it is helpful to maintain pieces that celebrate life, like birthday parties. Meaningful pieces of the old pattern act as familiar stitches that link pieces of the new normal.

What should I do? How should I be?

Children often struggle with guilt and worry when a parent is sick. They question, "Am I being good enough?" "Did I make my Mummy sad?" "I got mad about missing the band practice then Dad got so tired he had to go to bed - was it my fault?" Even older school-aged children need repeated reassurances that they in no way caused their parent's sickness. They need to know that it is normal for people to make mistakes and for family members to sometimes be mad at one another, even when cancer is in the family.

Children wonder about whether it is okay to have fun, to play with friends, and to leave their sick parent. These children need to know that when they are having fun, this is good news to their sick parent. What advice do children with a parent with cancer have for other children? "Be patient, do what you're asked to do, and help out at home." What do these children ask for in return? "Say thank you." "Notice how hard I'm trying." "Smile more." "Focus on life more than cancer."

The big question: "Is my mommy dying?"

The final and biggest life question is, "Is my parent dying?" I would like to introduce you to Harry, an eight-year-old I met when his parents brought him for counseling because of problems at school. He had been getting into trouble the year before, but the fall I saw him and his family things had really escalated. I learned as an aside that his dad had been recently diagnosed with cancer and had experienced surgery, radiation therapy, and was currently undergoing chemotherapy. Harry's parents were convinced that his difficulties had nothing to do with the cancer, but agreed for me to ask a few questions. I wondered

aloud if his difficulties concentrating at school might be related to worries about his dad. "Yes." I wondered aloud if he might be worried about whether his dad was sick and throwing up at home while he was in school. "Yes." I wondered aloud if he worried about his dad being all alone at home while he was at school. "Yes." I wondered aloud if he was worried that his dad was going to die. (very softly) "Yes." Harry's worries were getting in the way of managing well at school. Over the years, Harry and other children have taught us that even young children have an understanding about dying and death. Children will not usually ask the question, but this is a question that can be answered without it having been asked.

The nurse's role

What then, can we as nurses contribute to children and families when a parent has cancer? What role do we have? Isn't this someone else's job? Doesn't this take more time and skill? Certainly, nurses recognize the importance of working collaboratively with other professionals. However, we appreciate this perspective from Lewis (1990), "The major role of the nurse is to assist the family to self-right, not to "fix" the family; the family "fixes" itself in most situations" (p. 758). Let's consider four aspects of this kind of "self-righting" assistance. We begin helping families by understanding and appreciating the impact of cancer on the family. We can provide conscientious, systematic, ongoing assessment; awareness of children's questions, fears, and concerns; and use our knowledge and skill to help parents support their children.

Understanding the impact of cancer on the family

When cancer cuts across the fabric of life, it often affects different family members in different ways. Thus, it is important to remember that each child will experience the cancer differently and will respond differently. There is work for all the family members touched by cancer. Lewis (1999) defines this work as the integration of the cancer diagnosis and treatment into everyday life, "while still maintaining the family's life. Working through the illness is more than a cognitive-emotional process; it involves the development and refinement of often complex new behaviours of family members" (p. 319). Lewis describes this process as one of balancing two lives: "ongoing life as a family, and life linked to cancer" (p.319). Thus, new patterns, new structures, new colours, and new stitches are integrated to redesign the fabric of family life.

In her research with families, Hilton (1993) noted that, "learning to live with cancer is no easy task. Learning to live with someone else's cancer may be even more difficult" (p. 88). This learning touches every area of life: waking, sleeping, eating, working, playing, and loving. On a lighter note, Hilton reported that "children were often not enthralled by increases in bran, vegetables, fish, tofu and reductions in beef, fries, and junk food" (p.97).

Here is one mother's description of the quilt square that she designed to depict the impact of cancer on her life and the life of her children:

This square expresses the destruction of life as I had known it before the diagnosis of breast cancer and the life I have now. The burnt edge is the utter chaos that completely took over when I found out I had cancer. Dividing the square, the plain red fabric represents being in limbo, just trying to get through each day. The colours in my square are intense, almost violent, because I want my square to be beautiful, yet uncomfortable. Having breast cancer is a violent experience and the beauty and integrity of my life was not easily won.

The jury is still out on the impact of illness-related pressures for the children of families touched by cancer. However, as Lewis (1999) argues, "the absence of psychosocial morbidity does not address the possible level of undocumented distress, sorrow, unanswered questions, concerns, or disenfranchised grief the children and adolescents may be experiencing, which are essentially undocumented in the existing research literature" (p.324).

Conscientious, systematic and ongoing assessment

In assessing families, we begin simply. Ask about who's in the family. Ask the ages of children in the family to understand the developmental issues for the children as individuals and the family together. Ask about parents' concerns for their children and how they are working through them. Try asking, "How have you been able to explain to your children what's been happening to you?" and "What do you think they're wondering about?" and "What is going well in your family?" Acknowledge that cancer affects each person in the family, and identify yourself as someone who is interested in assisting families to make sense of what is often a very confusing and uncertain time. There may be others involved in working with a family - share your work, stitch together. This will broaden your understanding of the family's concerns, but also their resources, skills, and strengths. This is a work over time - an ongoing process as the family's cancer journey continues.

Awareness of children's questions, fears, and concerns

We know that children are concerned about the vulnerability of their parent with cancer. "Will my mom/dad be ok?" They need information about cancer and the treatment plan, they need an explanation of changes they see in their parents and in their family routines. We can raise parents' awareness of their children's concerns, and the importance of supporting their children, even when they themselves may be in "survival" mode. The longer they wait, the bigger it seems. Sometimes you just have to wade in!

Using knowledge and skills to help parents support their children

Parents are the best people to support their children. Nurses can use their knowledge and skills to help parents do this. Everyone has resources they've found to be "tried, tested, and true" - share ideas with colleagues in nursing and other fields. Think about all you know about the cancer journey and the demands of the disease and treatment on comfort and energy levels. Working together to relieve symptom distress makes much-needed energy available for parents to attend to their children's needs for love and support. As one parent observed, "It's pretty hard to do anything for your kids if you're too

Lung
Crossword
Puzzle Answers
Across
Down

from page 111...

1. Surgery	1. Smoking
2. First	4. Chestxray
3. Genetic	5. Cough
5. Chemotherapy	8. TNM
6. Metastatic	9. Bone scan
7. Brain	12. Adenocarcinoma
10. Five	14. Limited
11. Alopecia	15. Spirometer
13. Bronchoscopy	17. Marrow
16. Slow	20. Rapid
18. Bronchi	22. Extensive
19. Sixty	24. Sputum
21. Asbestos	25. Oatcell
23. Jaundice	26. Lobectomy
28. Nausea	27. Pneumonectomy

exhausted to move from the sofa." Resources like the CANO/JOI booklet **Your bank to energy savings** (1998) provide concise and concrete ideas to give parents energy to expend on their children. The Life Quilt's **Practical support in breast cancer** (1999) has many ideas for friends who would be blessed by helping out.

Think about what you know about the questions and concerns children have when a parent has cancer. You can help parents anticipate the important questions and the answers children need to hear. You can offer guidelines to help parents plan for talking with their children about cancer, cancer treatment, and living life in a family touched by cancer. Knowing what you do about patient and family education, you can offer information and practical resources in "digestible" pieces that parents can use, despite being overwhelmed by the demands of the illness experience. Joan Hamilton's book **When a parent is sick: Helping parents explain serious illness to children** (1999) offers practical and supportive information and suggestions. You can identify specific pages that outline ways to explain cancer and its treatment and ideas to help children at each developmental stage.

"Is my mom or dad going to die?" is one of the hardest questions of all. I (KJ) experienced this afresh in May as I looked into the faces of my 8-year and 11-year-old sons after my husband's heart attack - searching for the balance in hope and optimism, honesty and truth. I took courage from a woman I met who wanted help in telling her children about her breast cancer. Her condition had deteriorated very quickly, and she was moving in and out of consciousness. She was dying. Talking with this woman and her husband, I asked what they wanted their daughters to know about the situation now. The mother, in a voice barely audible, said, "to know that there's hope. No matter what happens, there's always hope." I think of her when I read this definition of hope: "Hope becomes more than a conviction that something will turn out well - it is the certainty that something makes sense and has meaning regardless of how it turns out" (Schlesselman, 1998, p. 88).

About blessings...

In three panels of the Life Quilt for Breast Cancer, artist Gay Mitchell depicts a devastating clear-cut, followed by signs of new life, and a forest healed and green. The movement of the images from clear-cut to new growth, and from new growth to the strength and majesty of mature forest, illustrates the hopefulness and potential in working with families touched by cancer.

Are there blessings to be found for children and parents? Yes, say kids and parents. Children are able to articulate the changes that cancer imposes on families - more tension, fatigue, worry, changes in food (more broccoli, less junk...), changes in activities, changes in people. They do, however, describe changes that they enjoy as a result of the cancer experience, ranging from "I get to watch more Digimon" (apparently that's good), "I get to have sleepovers at my friend's house," to "We spend more time together as a family, hanging out together," "We talk more about what's happening," and even "My school marks are better, because my mom helps me more. I care more about school, because that helps mom feel better." The literature suggests that life with cancer offers children opportunities to learn other life lessons: "You're the same person on the inside," even when there are outside changes; "Sometimes you have to lose things to get other more important things"; "Sometimes you have to wait and work to get what you want"; and "You can learn to adjust to unwanted changes" (Harpham, 1997a) - even changes worse than tofu and vegetables.

Speaking as a parent with cancer, Wendy Harpham (1997a) offers this encouragement, "The greatest gift you can give your children is not protection from change, loss, pain or stress, but the confidence and tools to cope and grow with all that life has to offer them" (p.13). The gift is powerful and life-sustaining. It is a gift that grows and changes over time. It is a gift to which we can contribute.

As oncology nurses, we are part of a community of healers, assisting families in piecing together a quilt of wholeness, of love, and of hope, from the fabric of life cut by cancer. ♣

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