# Chapter 3
# Patient and Family Tools to Aid in Education and Decision-Making About Oncofertility

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When an adolescent or young adult (AYA) patient is facing cancer treatment, potential loss of fertility may not be the first thing on his or her mind. Patients often describe their immediate concern is "getting rid of the cancer" or wondering if they will survive. While these concerns are normal, addressing fertility preservation prior to the initiation of cancer treatment provides the most optimal options and opportunity for success. The majority of female AYA patients, based on recent literature, choose not to take steps to preserve fertility, but overwhelmingly appreciate being informed about potential loss of fertility [1]. The reasons for not using fertility preservation among females include financial costs, lack of a male partner, unwillingness to use donor sperm, and the perception of an inability to delay treatment [2, 3]. About 50 % of AYA males chose to bank sperm prior to cancer treatment and among those who do not, feelings of regret and remorse are often cited [4]. Males also report appreciation for the information, yet are more likely to recall they had not thought about and/or were embarrassed to discuss sperm banking and future children with their parents or healthcare professional.

How does a cancer patient make a decision about whether or not to pursue fertility preservation? The risk of potential fertility loss should be conveyed to patients by oncologists early in treatment planning, as suggested by the American Society for Clinical Oncology. When the oncologist is uncertain about the threat to fertility or what options may be available to the patient, ASCO also recommends that a referral be made to a reproductive endocrinologist or infertility specialist. However, receiving the medical information regarding potential fertility loss is just one component of the decision-making process. Decisions about fertility preservation

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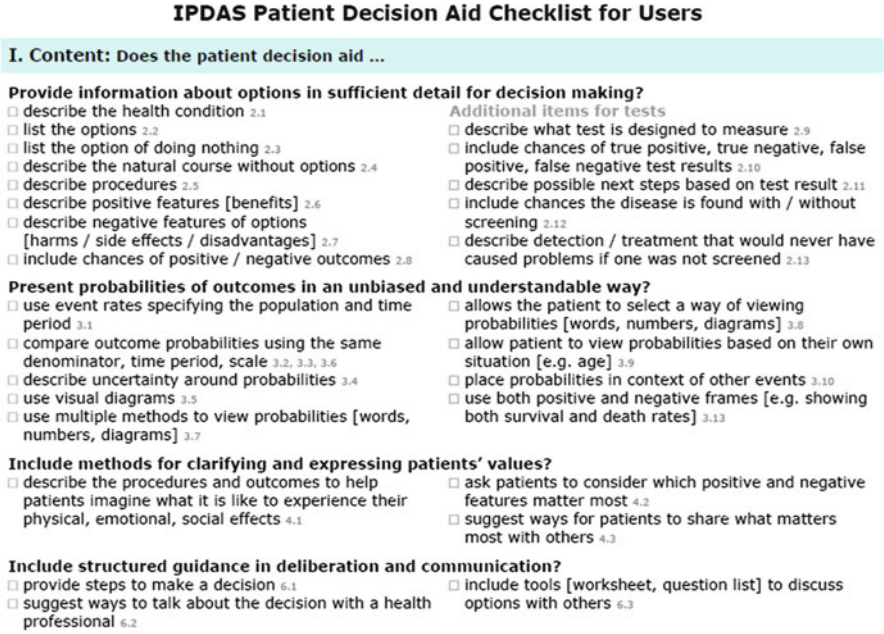
may be considered to have three components: risk appraisal, information integration, and long-term consideration.

In one component, the patient must appraise and comprehend the amount of risk associated with pursuing fertility preservation options. These risks may be cancer-related, such as the effect of treatment delay on cancer outcomes, as well as risks associated with the fertility preservation options themselves. The risk may also be psychological: how will the patient feel if she becomes infertile and did not take steps to preserve her fertility? It is also possible that for newer and more experimental options, patients may have to contend with an unknown or unappraisable likelihood of success. Based on this appraisal, the patient must decide if these risks and uncertain benefits are acceptable. To make these decisions, the patient must also consider present and future desire for a biological child. Added to this is the consideration of the patients' perception of mortality in light of the diagnosis and whether a limited life span has an impact on decisions about having a biological child. However, people tend to be poor forecasters of what they will want in the future [5]; this is especially true of teens and adolescents. A second component, which may occur concomitant with other decision-making processes, involves assessing information about the fertility preservation options, the medical procedures, the costs for the procedure and storage, the patient's current relationship status, health status, and religious, ethical, or moral concerns about these options. Steps one and two may not happen in a linear fashion and a patient may move back and forth between these components in the decision-making process.

The third component is one which is often not considered until years later, but we suggest it should be considered at the same time as the other two components. This component relates to retrieving the stored sperm, embryo, oocytes, or tissue. How will the patient feel about using assisted reproductive technology (ART) to become a parent? When will a patient be assessed for return of fertility posttreatment? If the patient regains fertility, will he or she continue to store gametes or embryos? How will long-term storage be financed? For men this may mean their female partner becomes the patient when stored sperm requires the use of ART for insemination. For women this may mean decisions about how long to store embryos, what to do with unused oocytes, or asking a partner to parent a child born from donor sperm or eggs. Thinking about these issues at the time of making fertility preservation decisions can be seen as analogous to the need to begin survivorship planning at the time of diagnosis.

The issues for decision making in fertility preservation among cancer patients are complex and intricate. As such, tools to support patients in this process, including decision aids, are limited. Decision support tools and decision-making strategies may be useful for the healthcare professional or researcher working with AYA cancer patients.

The criteria for what constitutes a patient decision aid are quite specific. According to the International Patient Decision Aid Standards (IPDAS) Collaboration, a decision aid prepares a patient for decision making by doing three things: (1) providing facts about the patients condition, options, and features (2) helping people to clarifying their values (the features that matter most to them) and



**IPDAS Patient Decision Aid Checklist for Users**

**I. Content: Does the patient decision aid ...**

**Provide information about options in sufficient detail for decision making?**

- ☐ describe the health condition 2.1
- ☐ list the options 2.2
- ☐ list the option of doing nothing 2.3
- ☐ describe the natural course without options 2.4
- ☐ describe procedures 2.5
- ☐ describe positive features [benefits] 2.6
- ☐ describe negative features of options [harms / side effects / disadvantages] 2.7
- ☐ include chances of positive / negative outcomes 2.8

Additional items for tests

- ☐ describe what test is designed to measure 2.9
- ☐ include chances of true positive, true negative, false positive, false negative test results 2.10
- ☐ describe possible next steps based on test result 2.11
- ☐ include chances the disease is found with / without screening 2.12
- ☐ describe detection / treatment that would never have caused problems if one was not screened 2.13

**Present probabilities of outcomes in an unbiased and understandable way?**

- ☐ use event rates specifying the population and time period 3.1
- ☐ compare outcome probabilities using the same denominator, time period, scale 3.2, 3.3, 3.6
- ☐ describe uncertainty around probabilities 3.4
- ☐ use visual diagrams 3.5
- ☐ use multiple methods to view probabilities [words, numbers, diagrams] 3.7
- ☐ allows the patient to select a way of viewing probabilities [words, numbers, diagrams] 3.8
- ☐ allow patient to view probabilities based on their own situation [e.g. age] 3.9
- ☐ place probabilities in context of other events 3.10
- ☐ use both positive and negative frames [e.g. showing both survival and death rates] 3.13

**Include methods for clarifying and expressing patients' values?**

- ☐ describe the procedures and outcomes to help patients imagine what it is like to experience their physical, emotional, social effects 4.1
- ☐ ask patients to consider which positive and negative features matter most 4.2
- ☐ suggest ways for patients to share what matters most with others 4.3

**Include structured guidance in deliberation and communication?**

- ☐ provide steps to make a decision 6.1
- ☐ suggest ways to talk about the decision with a health professional 6.2
- ☐ include tools [worksheet, question list] to discuss options with others 6.3

**Fig. 3.1** IPDAS patient decision aid checklist. Permission from Anton Saarimaki, OHRI

(3) helping people share their values with their healthcare practitioner and others. The IPDAS has developed a set of criteria to determine the quality of patient decision aids. A "users' checklist" summarizes the standards that determine whether or not a decision aid is a source of reliable health information that can help in decision making [6]. The values clarification process may be particularly important with respect to fertility preservation, as there may be uncertainty surrounding disease outcome and survival as well as uncertainty about the success of fertility preservation techniques themselves (Fig. 3.1).

While the IPDAS provides recommended criteria for patient decision aids, the Ottawa Decision Support Framework (ODSF) offers a three-step process for a strategy to address the conflict experienced by patient in the medical decision-making process. Using concepts and theories from general psychology, social psychology, decision analysis, decisional conflict, values, social support, and self efficacy, the ODSF is an evidence-based theory for guiding patients in making health decisions [7, 8]. The three-step process assesses patient and practitioner determinants of decisions to identify decision support needs; provides decision support tailored to patient needs; and evaluates the decision-making process and outcomes (Fig. 3.2).

While IPDAS and ODSF provide structure for the design and development of patient decision aids and decision support strategies, Learner Verification (LV) is a framework that helps ensure the materials developed (e.g., decision aids, decision support strategies) are suitable for the intended audience and better matched to patients' learning needs [9]. LV provides an excellent framework for the health

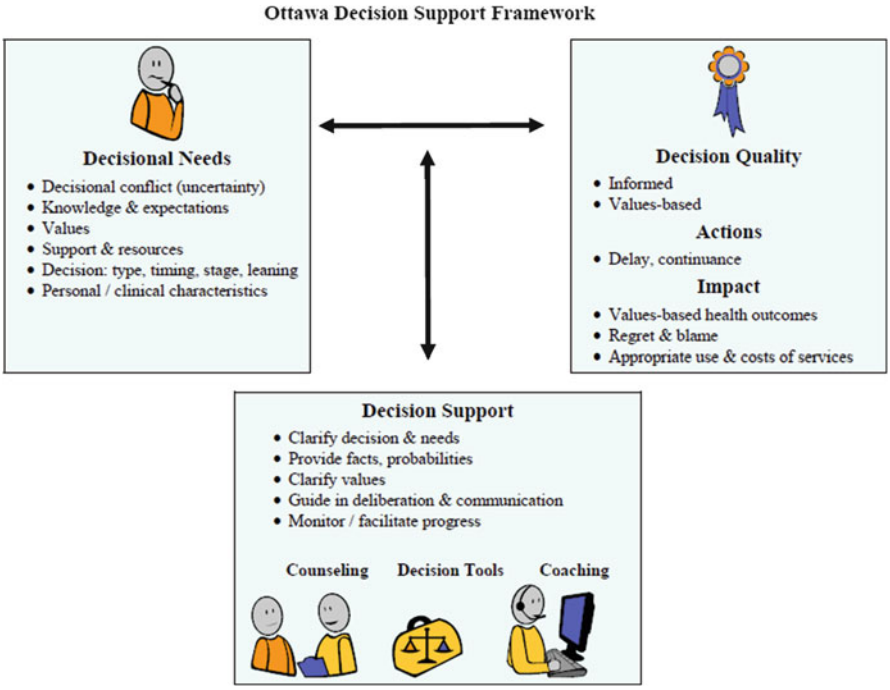



**Fig. 3.2** Ottawa decision support framework. Permission from Anton Saarimaki, OHRI

communication challenge of developing materials with effective messaging [10]. LV is rooted in information processing theory, focusing on the persuasiveness of a health message and provides a systematic process for assessing the intended messages of a decision aid or educational materials [10]. Specific components of LV are typically assessed with the target audience (the specific group for whom the material is intended, e.g., AYA cancer patients considering fertility preservation). These components include Attractiveness, Comprehension, Cultural Acceptability, Self-efficacy, and Persuasion (4). LV is a quality control process and technique that helps ensure materials are suitable for the intended audience and better matched to patients' learning needs [9] (Table 3.1).

## Examples of Oncofertility-Related Educational Materials and Decision Aids

As another chapter in this volume will present provider-oriented decision support, this section focuses on patient and family-oriented educational tools and decision aids. Institutions and healthcare professionals may wish to create their own educational materials or decision aids based on knowledge of their own patients or their

**Table 3.1** Elements of learner verification assessed in study brochure

| Elements of Learner Verification assessed | Questions from interview guide |
|---|---|
| Attraction (Does the material appeal to the target audience?) | What about the appearance of this brochure intrigued you?<br>If you were sent this brochure in the mail, would you want to read it to find out more about breast cancer? |
| Comprehension (Does the target audience understand the material?) | Tell me in your own words what you think the purpose of this brochure is?<br>Did this brochure help you to understand the purpose of genetic testing?<br>Are there any risks in your family that would make you want to have genetic testing? |
| Self-efficacy (Does the target audience feel the message is doable for them? | After reading this brochure, would you want to participate in this study? (probes: If you wanted to participate would you be able to?)<br>Did this brochure help you to understand why genetic testing is important to African American women with breast cancer? |
| Cultural acceptability (Does the target audience perceive the message to be salient and acceptable?) | How do feel about the phrase "Women of Color"? (probes: Do you think most African American women would feel the same way?; Do you think there is another term that African American women identify with?)<br>Is there anything in this brochure that makes you feel uncomfortable about genetic testing?<br>Do you relate to any of the women in this brochure? |
| Persuasion (does the message convince the target audience to take action?) | If you received this brochure in the mail, would you want to have a genetic test for *BRCA*?<br>Do you think your family and friends might have genetic counseling/testing if they received this brochure? |

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institutions' policies, guideline, and resources. The following is a list of existing tools and strategies related to oncofertility that may serve as a guide for developing practice-specific tools. Practitioners may also choose to use these materials or modify them as allowed and applicable.

## *LiveStrong/Fertile Hope Brochure and Website [11]*

This website includes a risk calculator, downloadable materials for healthcare professionals, different groups of cancer patients (male, female, pediatric) and provides links to the Sharing Hope program. This program provides need-based financial assistance to patients for using fertility preservation (Fig. 3.3).

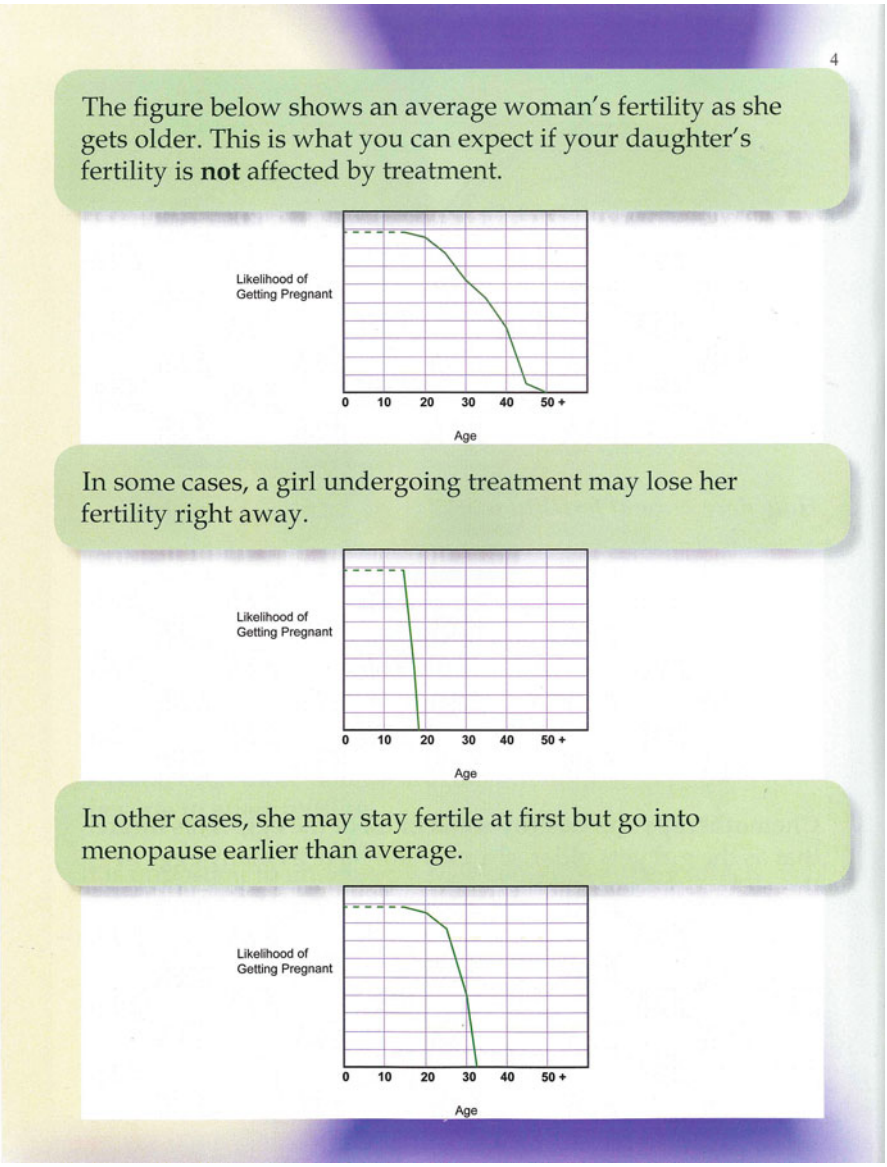


**Fig. 3.3** FertileHope.org Website. Permission from Dr. Sarah Arvey, LIVESTRONG

## *Oncofertilty Website [12]*

The Oncofertility Consortium maintains a website that has both provider and patient-oriented content. Patient content can be found at http://www.myoncofertility.org/printresources as well as http://oncofertility.northwestern.edu/patients/fertility-preservation-options-nu. In addition to information about fertility preservation,


**Fig. 3.4** MyOncofertility.org Website. Permission from Dr. Teresa Woodruff, NW

these resources include animated sequences that describe how and why fertility may be threatened by cancer treatment as well as the fertility preservation options. The website also includes testimonials by patients and providers. The website was developed as part of the Oncofertility Consortium's outreach efforts and has also been translated into Spanish (Fig. 3.4).

## *Web-Based Decision Aid [13]*

This collaborative project between a reproductive endocrinologist, clinical psychologist, and oncology expert involves an interactive, web-based decision aid designed to be used in concert with fertility preservation counseling. The goal of the decision aid is to develop and make available a web-based tool that could be used for patients who do not have easy access to a full fertility preservation consultation with a reproductive endocrinologist (Fig. 3.5).

## *"A Young Person's Guide to Cancer and Fertility": Male and Female Brochure [14]*

The majority of patient information on FP was designed by and for adults, and may not be appropriate for pediatric populations. These brochures were developed for a specific children's hospital after a review of available literature and existing

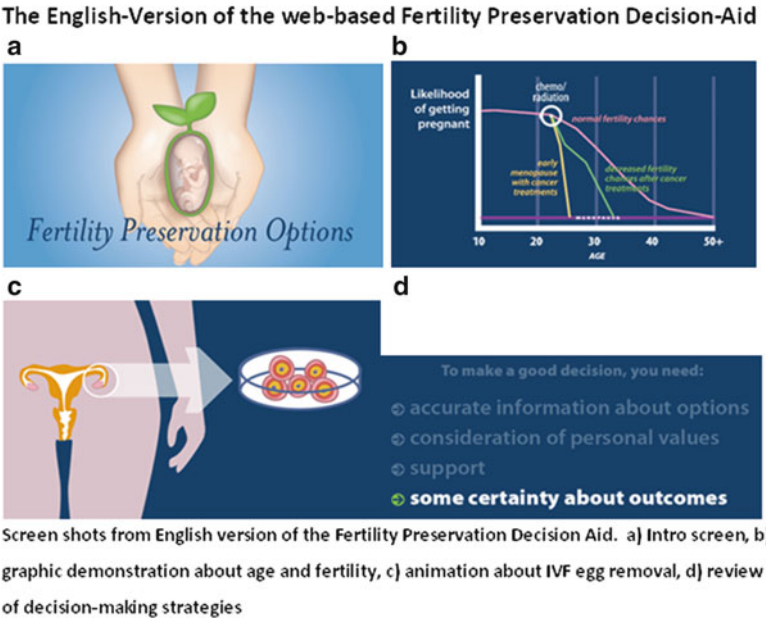


**Fig. 3.5** Web-based fertility preservation decision aid. Permission from Dr. Jennifer Mersereau, UNC

educational materials. First, the research team designed a preliminary brochure outlining cancer-related infertility and the options available for pediatric patients. Due to the vast differences between female and male fertility issues and options, a separate male and female brochure was developed. The brochures were tested with three groups (patients and survivors aged 12-21 ($N=7$), their parents ($N=11$), and healthcare providers ($N=6$)). The final brochures were revised based on majority feedback and feasibility (Fig. 3.6).

## *Fertility-Related Choices: A Decision Aid for Younger Women with Early Breast Cancer [15]*

This is a booklet for young women who have recently been diagnosed with early breast cancer. As chemotherapy and hormonal therapy may decrease fertility and reduce the chance of having children in the future, the information provided here is designed to help women decide which, if any, of the available fertility options are of interest to them. This booklet was specifically designed for the following patient characteristics: recently diagnosed with early breast cancer and reproductive age (having regular periods and no menopausal symptoms), and thinking of starting a family or having more children in the future (Fig. 3.7).


**Fig. 3.6** A and B: A guide to cancer and fertility for female pediatric patients, a guide to cancer and fertility for male pediatric patients. Permission from Dr. Gwendolyn Quinn, MCC

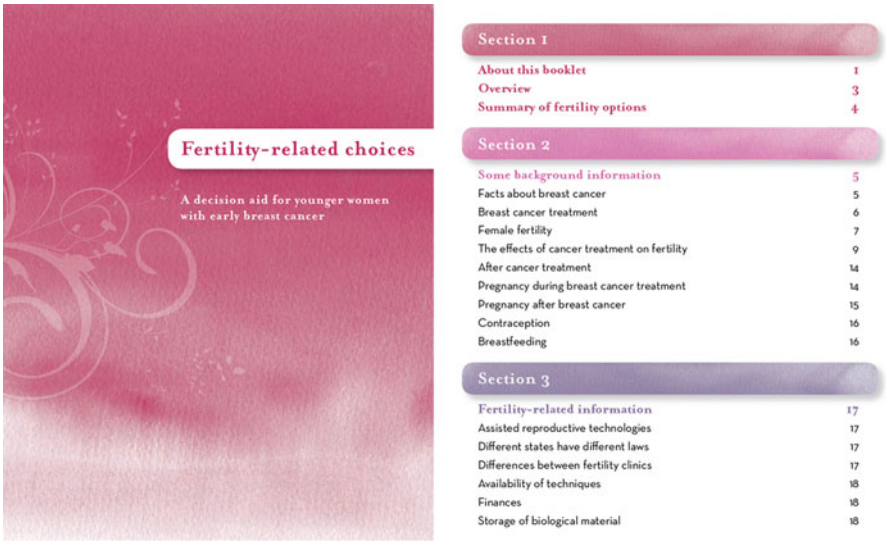


**Fig. 3.7** Fertility-related choices: a decision aid for younger women with early breast cancer. Permission from Dr. Michelle Peate, UNSW

## *Adolescent Fertility Values Clarification Tool [16, 17]*

This tool was designed to provide healthcare providers with a platform for discussing the impact of cancer treatment on future fertility with adolescent females. It discusses the preservation options and provides an approach for allowing the teen to consider her knowledge, desire, and value of parenthood. Since this is a tool, and not an instrument, there is no scoring guide. The tool will help practitioners assess the patient's values and understanding of fertility in relation to the cancer diagnosis and treatment plan. The tool provides examples of common coping techniques used by teens during the piloting and testing of the instrument (Fig. 3.8).

## *Learning About Cancer and Fertility: A Guide for Parents of Young Girls [18]*

This decision aid was designed for parents of young girls diagnosed with cancer. Through interviews with parents ($N=20$), the developers chose to develop a paper-based tool that acknowledges parents' focus on their child's survival than future fertility. The decision aid explains that some cancer treatments can affect their daughter's fertility in both short and long term and there may be decisions parents


Adolescent Fertility Values Clarification Tool

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**Fig. 3.8** Adolescent fertility values clarification tool. Permission from Dr. Gwendolyn Quinn, MCC

can make to preserve their daughter's fertility. Due to the age of the patients whose parents are the target of this decision aid, experimental options are also described. The focus of the tool is not just for making fertility preservation decisions but also serves as a guide to give parents information that will help them talk with their child's healthcare team now and in the future as she grows (Fig. 3.9).

This is not a comprehensive list of all tools and materials available on the topic of fertility preservation among AYA populations but serves as a sample of those that were developed with multidisciplinary teams and with a scientific approach. It is important for healthcare providers and researchers to explore decision aids and educational strategies that may improve the understanding of fertility preservation and its limitations. Healthcare professionals may consider which of these existing tools is appropriate for the institution and the population or if tailored tools should be developed based on unique characteristics of the patient population. Cancer survivors value the ability to make an informed decision about their future fertility preservation options. While decision aids, tools, and strategies are not a replacement for a discussion with a medical professional, they can assist patients and survivors with peace of mind about their choices.

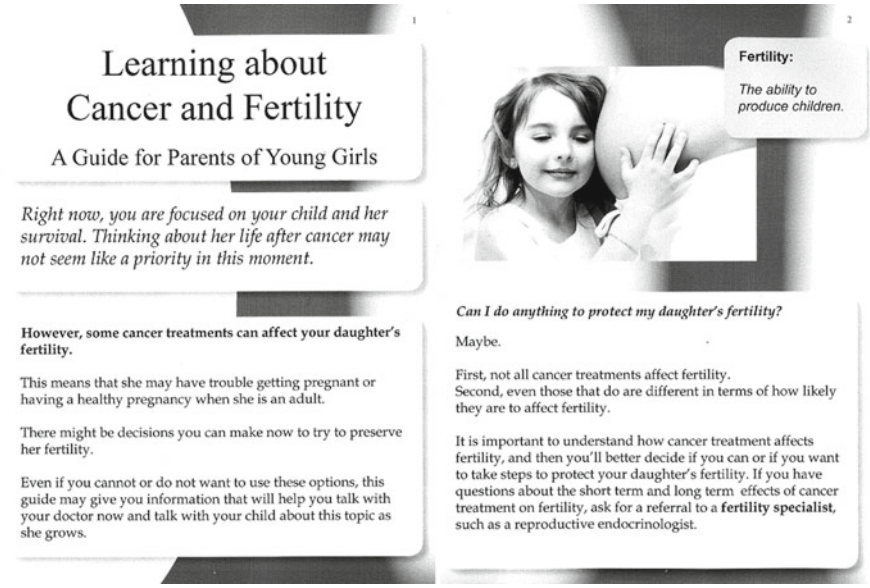


**Fig. 3.9** Learning about cancer and fertility: a guide for parents of young girls. Permission from Dr. Marla Clayman, NW

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