

Figure S1. The paradigm model for the category ‘Guided by the doctors: accepting the long-term prescription’, explains the complex events when women are first prescribed hormone therapy for the long term management of their breast cancer

Context: Completing the acute stage of treatment for breast cancer <i>The care of women being treated for breast cancer, in the UK guided by the National Institute for Health and Care Excellence (NICE), involves treating women with chemotherapy, radiotherapy or surgery at the acute stage and with long-term treatment with a hormonal drug given as appropriate</i>				
Trust in their health care provider	Causal conditions	Actions/interactions	Consequences	Worries and expectations
	Transitioning into a new stage of breast cancer treatment Being overwhelmed by information provided all at once Fear of cancer recurrence Fear of possible side-effects of the new treatment Lack of specific information and uncertainty about the medication (<i>necessity, efficacy, safety and mechanism of action</i>) Feeling vulnerable The memory of difficult experiences during the initial stage of the treatment (<i>at a personal level, professional level or emotional level</i>)	Having a consultation about the medication where it is prescribed Accepting or deferring the treatment (<i>dependent on e.g. trusting their health care provider advice, awareness of the necessity of the medication, the level of stability in family and social life, emotional stability and support, desire to continue living cancer free, comorbidities, need of normalcy</i>) Women taking care of themselves Women looking for information elsewhere (<i>through specialized websites, specialized forums or from other patients</i>)	Going along with the hormonal prescription Delaying the hormonal treatment Transitioning into the long-term treatment phase with ease (<i>trusting the treatment and finding the necessary support</i>) Having difficulties transitioning into the long-term treatment phase Being well informed by receiving the correct information (<i>not looking for information in the wrong places and correcting misconceptions about the treatment</i>) Being wrongly informed about the medication (<i>side-effects, mechanism of action, efficacy and safety</i>) Less hospital visits (<i>less communication with health care providers</i>) Guided by the doctors: accepting the long-term prescription	
Knowledge about the treatment				





Figure S2 The paradigm model for the category ‘Balancing priorities: adhering to the long-term treatment’, explains the complex events when women are managing their hormone therapy in breast cancer survivorship





Context: Accepting a prescription for adjuvant endocrine therapy				
Women are prescribed tamoxifen or aromatase inhibitors as adjuvant therapy after surgery, radiation or chemotherapy for breast cancer. Guidelines recommend the use of tamoxifen in pre- and post-menopausal women for 5 years and could be extended more than that if needed. Also, the extended use of aromatase inhibitors after the initial 5 years after diagnoses has been encouraged in post-menopausal women				
Ability to adapt to the side-effects of the treatment	Causal conditions	Actions/interactions	Consequences	Knowledge about the treatment
	Trust and belief in the treatment and its necessity versus fear of treatment and its side-effects Wanting to continue living cancer free (realizing necessity of the treatment) and fearing cancer recurrence (anticipating regret) Receiving correct information about the treatment and side-effects in advance Need for knowledge vs preference for not knowing (psychological burden) Severity of side-effects experienced or feared (e.g. <i>menopausal or psychological</i>) Ease of access and availability of professional support and perceived their trustworthiness Wanting support from family, friends, co-workers and other patients. Obligations to family to get well and owing it to others to live Expense of the medications (insurance issues)	Incorporating medication into routine and watching for changes in usual routine Looking for appropriate support from specialists, GPs, nurses, pharmacists, support groups, family and friends Looking for other sources of information Trying to manage the side-effects Experimenting with alternative medicine Discuss the possibility of changing the hormone therapy medication Modifying life to adapt to the treatment and its side-effects (e.g. <i>quitting work due to lack of energy, downsizing, changing other routines such as sport/exercise, social activities, travelling, housework and frequency of sexual intercourse, taking up healthier eating habits</i>) The use of coping mechanisms to ease the experience (e.g. active coping and self-motivation, seeking physical and emotional support, maintaining a positive attitude, meditating, acceptance, humour)	Adhering to the treatment despite being surprised by the challenges and the severity of the side-effects (i.e. finding adherence to be more difficult than originally thought) Forgetting to take the treatment as prescribed occasionally or taking a drug holiday to manage side-effects Committing to finishing the whole duration of the treatment Putting up with side-effects of the treatment Restricting social activities Side-effects of the treatment, old age and other medications get entangled Cancer and feeling ill linger throughout the treatment Balancing priorities: adhering to the long-term treatment	
Support received throughout the treatment				





Figure S3 The paradigm model for the category ‘Taking a chance: stopping the treatment early’, explains the complex events when women are deciding to stop their hormone therapy ahead of time

Context: Adhering to the medication and experiencing the side-effects <i>After starting the treatment and committing to adhere, women start to experience the medication side-effects, which is unexpected or more severe than they had imagined or expected</i>				
Quality of life taking precedence over longevity of life	Causal conditions	Actions/interactions	Consequences	Continuous search of normalcy
	Severity of the treatment sever side-effects Poor quality of life No trust in the treatment (i.e. negative perceptions of the treatment) Fear of the possible side-effects Being given the choice to stop the treatment by the healthcare provider Faith and religion A sense that existing adherence has already conferred therapeutic benefit Lack of support during the treatment Lack of trust in the healthcare providers and the medical system	Communication with health care providers and deciding to stop the treatment Stopping the treatment without communicating with anyone	Stopping the treatment early Accepting that death is not the worst option Better quality of life Regaining control Having a sense of normalcy Taking a chance: stopping the treatment early	
Beliefs about the treatment necessity				

Figure S4 The pictograms that required modification, their I-CVI and recommended changes.

No.	Description	Pictogram	I-CVI	Changes recommended
1.	Experiencing difficulties during the initial stage of the treatment (personal level, professional level or emotional level)		0.5	Draw someone pulling their hair
2.	Being wrongly informed about the medication (side-effects, mechanism of action, efficacy and safety)		0.7	Add a patient face
3.	Trust and belief in the treatment and its necessity		0.7	Draw thumbs up to a pill or a tablet instead of shaking hands
4.	Receiving the correct information about the treatment and side effects in advance		0.6	Draw a book and a happy face

5.	Changes in the patient's usual routine		0.5	Draw someone going on holiday
6.	Trying to manage the side effects		0.6	Draw someone suffering from hot flushes (face sweating)
7.	Lifestyle modifications to adapt to the treatment and its side effects: Quitting work due to lack of energy, moving to a smaller house, routine changes (sport, social activities, travelling, housework and sexual intercourse), living healthier (diet and exercise)		0.7	Add a drawing of someone running and doing yoga
8.	Ability to adapt to the side effects of the treatment		0.7	Draw a suffering face and a happy face

9.	No trust in the treatment (negative perception of the treatment)	 <p>No trust in the treatment</p>	0.6	Instead of a hospital, draw pills, tablets or both
10.	Fear from the possible side effects	 <p>Fear of side-effects</p>	0.7	Draw the face of someone thinking of bad things
11.	Lack of physical and emotional support during the treatment	 <p>Lack of support</p>	0.6	Draw a crowd of people with the main person isolated
12.	Lack of trust in the health care providers and the medical system	 <p>No trust in health care system and providers</p>	0.6	Add a doctor next to the hospital


13.	Patient accepting that death is not the worst option		0.5	Draw someone dancing
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Table S1: Breast cancer survivors' comments about the schematics and pictogram representation in relation to their own experiences and in terms of their usefulness.

Do you find yourself in the pictogram?
<p>“Yeah, but yes I can identify with many of those things. Not all but yeah, to some degree most of them, yeah.” Interview 1</p> <p>“I do, yeah I can relate to a lot of that without even thinking that I probably was in that little cycle that you’ve just done that...” Interview 3</p> <p>“Yeah. That is me to a tee. That’s quite scary. Yeah, that is quite scary.” Interview 6</p> <p>“Yeah definitely a part.” Interview 7</p> <p>“Yes I do. In almost all of the boxes.” Interview 8</p> <p>“Yes, I think so. I think there and there probably and accepting and then trying to do some of those.” Interview 9</p> <p>“I do, yes. Yes. Most definitely.” Interview 11</p> <p>“I think I recognize myself in quite a lot of that as well.” Interview 12</p> <p>“Yes I do. I recognize all of that” Interview 14</p>
Would you like to add anything to the pictogram?
<p>“No, I think that sums it up very well actually and it’s helped me to tell you more about my treatment cycle.” Interview 2</p> <p>“No, that’s it, yeah.” Interview 5</p> <p>“No. I think that is absolutely true in every one of those, yeah, definitely.” Interview 6</p> <p>“No, I don’t think so. I think that is spot on.” Interview 6</p> <p>“No I think you have included pretty much everything to be honest.” Interview 8</p> <p>“No, I think you have captured everything to be honest.” Interview 8</p> <p>“Wow. Well done, that's perfect actually, that's captured everything to be honest. Yeah well done.” Interview 8</p> <p>“No, that’s very thought-provoking.” Interview 9</p> <p>“Yeah, no I think it yeah it does cover, every little one of them I can see myself in, yeah. So yeah, that’s good. It seems to have covered, I can't think of anything that you haven't put on there, so...” Interview 10</p> <p>“No. I think that’s, that’s probably right.” Interview 11</p> <p>“I think it covers all the things that are if you like the negatives that people come across and that would influence them on continuing to take the treatment. Yes, very much so.” Interview 13</p> <p>“No, I think that’s really, really good, I think that will be really helpful.” Interview 14</p>
Do you think these pictograms are useful? How? And to whom?

“Yes, it does. Yes, oh right that’s a useful diagram.” Interview 2

“Yeah let’s just hope that something comes of it, that it helps to, yeah.” Interview 10

“And you go, yeah, yeah, it is, in fact it’s normal because that’s what I felt. So it then validates the fact that I was feeling it must be OK because someone else has felt it so I wasn’t going mad, if you know what I mean.” Interview 11

“I think it would actually because, you know, for example, the consequences of the cancer feeling lingers on. That will, if I knew that, that, that’s, that studies report that, then I wouldn’t have spent so many hours thinking I was actually going mad. And it was only when my, another one of the ladies mentioned it about, you know, I can’t stop thinking I’m going to die, that I was able to say, oh I felt like that. So, it normalized it for both of us.” Interview 11

“Yes, yeah, because it’s setting out all of the possibilities of what’s likely to happen and you can think, well, some will and some, you know, and as long as you’re told, well, some will and some won’t, you know.” Interview 11

“Wow. That is really good. That does encapsulate exactly how it feels, in a way. Gosh.” Interview 11

“Yeah, no worries. I mean, I’m hoping your thesis or dissertation or whatever it calls, whatever comes of all of your studying will actually make it. I certainly think if I’d have had some of these pictures to look at before, you know, sort of, five or six years ago, it would have helped me, not, I mean, I don’t suppose for a minute it would stop me thinking I was going mad but it would help thinking, well, hang on a minute, that is normal.” Interview 11

“I think this is fantastic. Absolutely.” Interview 11

“Yeah, that is really good because there are very many GPs who are, I mean it’s something like one in eight women get breast cancer and it’s only about 10% don’t take hormonal therapy so actually this would be very helpful particularly as it is something quite new for them to have to deal with.” Interview 13

“I think that’s really great for the GP, yeah. Thank you. Or for anybody that’s involved in prescribing or giving out information.” Interview 13

“Oh, very much so, yes. I do think that because what it does is it puts it in their mind that they’re not on their own as it were. So, yeah, so from that point of view it makes it easier to understand that there are, while it is a very positive thing for your general health at the time that it’s not straightforward and there could be problems but which can be managed.” Interview 13

“Yes I do. I do actually, I think it gives a framework and stages and well some of it’s stages isn’t it? I think it would help the healthcare provider as well, it gives a focus that isn’t lengthy written information. I think it is very good and I like the pictures and everything.” Interview 14

“I think that they ought to take, this is such strong medication that actually they ought to approach it in that way and review it using the kind of framework you’ve got here.” Interview 14

“It would help me if I was say a breast care nurse or something like that I would find this very, very helpful to go through. I would find it also if I was a, I’m doing this from a nursing point of view, because that’s my background, but I would actually look at the education needs of staff if I was a manager in terms of their preparation, in-house also if we send staff on courses does it cover this kind of thing, how do

they demonstrate that they're competent in all of this. I would, that's what I would be looking for. And I think doctors would benefit from, at least following, I think some of them do but it's going in more depth. Or knowing, having somebody in the team who can do this. They don't all have to be expert at it, but somebody who can. I think it will be very, very good." Interview 14

"Yes and I like the way you've done it. I like the way, I like all of your, the pictures you've got as well." Interview 14