A learning resource for healthcare teams who want to know and understand more about supporting people with long term conditions to self manage

Version 1

This resource is available electronically at: www.nes.scot.nhs.uk/selfmanagement

© NHS Education for Scotland 2012. You can copy or reproduce the information in this document for use within NHSScotland and for non-commercial educational purposes. Use of this document for commercial purposes is permitted only with the written permission of NES.
What is Anna's Story?

Anna’s Story is a learning resource for healthcare teams who want to know and understand more about supporting people with long term conditions (LTC) to self manage. It could also be used with wider multi-agency teams.
Anna’s Story comprises;

1. A DVD of Anna and her daughter telling their story. It is done as a ‘fly on the wall’ style documentary; it has eight scenes set over an 18 month period. It shows Anna’s response to getting a diagnosis of a LTC, and some of the ways it impacts on her and her family.

2. This facilitators handbook which provides group discussion questions linked to each of the eight scenes.

Who is it for?

Anna’s Story has been designed for use with teams. This could be uni-professional, multi-professional or multi-agency. It’s based on facilitated conversations and encourages participants to reflect on their own, and their team’s practice, in relation to supporting self management. It is therefore best done with everyone who is in the team, or contributes to the team.

What is its purpose?

Anna’s Story aims to enable teams to gain a deeper understanding of their practices, relationships and organisation processes which support self management. It is not focused on learning a whole new set of skills or on ‘doing more’. It is about supporting staff to explore using their existing skills, knowledge and organisation processes in different ways. It will:

1. Encourage teams to consider their beliefs, actions and behaviours in relation to supporting self management.

2. Invite people to reflect on the contradiction between what is desirable and actual in practice.

3. Give people the opportunity to learn from each other and to understand and put into practice ways of supporting people with LTCs to self manage.
Who is Anna?

All of the characters in *Anna’s Story* are fictitious and played by actors. However they are based on the experiences of people living with LTCs. In the DVD Anna is given a diagnosis of rheumatoid arthritis (RA) but the DVD is not about one particular condition. RA is used as an example condition to highlight some of the experiences which apply to many people living with a LTC. The characters you see or hear about in the DVD are:

**Anna**
Anna is the main character in the story.

**Arran**
Arran is one of Anna’s grandsons.

**Bess**
Bess is Anna’s daughter with whom she has a close relationship.

**Dave**
Dave is Anna’s partner. We hear her talk about him, but we never see him.

**The documentary maker**
We occasionally hear the documentary maker asking Anna a question.
How can it be used?

Anna’s Story has been designed as a resource for facilitated group discussion. It is not a prescriptive programme, rather it provides the foundations for a workshop which can be delivered flexibly as;

1. A full day (or two half days) workshop using the DVD and facilitators pack as the framework for the day (adapting to suit as necessary). It can be used to bring together people from different agencies to explore the range of perspectives and contributions each agency brings to supporting self management. This can be part of the process of developing and realising a shared vision and common purpose.

or

2. A series of short one or two hour facilitated sessions with the team. Where possible this would be best done within the work environment e.g. by ‘piggy backing’ on to existing opportunities such as team meetings. The materials can be tailored to suit the needs and time capacity of staff and services.
Notes for facilitators

Using the resource

1. This resource offers the main structure of the workshop/session but you can adapt, tailor or expand to suit the specific circumstances. It therefore does not contain lots of prescribed or detailed instructions, session timings or workshop plans.

2. There are eight scenes to watch and after watching each scene there are a number of questions for you to ask the participants in order to facilitate discussion.

3. The questions provide focus on a key topic in each scene. The initial question(s) are related to the story and the last question (extension question) takes a broader view around the topic.

4. Each question is preceded by a short paragraph which introduces the learning points or themes. You could use a number of options to share this with the group e.g. make PowerPoint slides, use flip charts, or talk through.

5. Many of the scenes also touch on issues which are not addressed in the questions. You could choose to look at some of these additional issues if you felt it was particularly relevant to the participants.

6. It would be helpful if you provide some context to the question(s) which resonates with the working environment of the participants e.g. if you have a group of practice nurses set the question in the context of primary care.

7. This resource is about supporting people to consider different perspectives and where appropriate make small changes to their practice and/or processes which might be more supportive of self management.

8. Using this resource may highlight some learning needs in related areas e.g. risk enablement, health coaching or approaches to self help.

9. As you work through the activities look for opportunities where the learning and discussions taking place can be translated into actions or incorporated into improvement processes. For example, auditing a sample of documentation to see if they reflect a strengths approach, action plan for reviewing assessment forms/clinic invites, commitment to add record of self management conversations to pro-forma.
Facilitation style

1. This is a conversation and reflection based resource therefore participants need time to consider and fully discuss their responses.

2. This pack needs an approach that mirrors supporting self management i.e. where the function of the facilitator is to facilitate the discussion and support people to arrive at their own solutions or ideas, rather than imposing the ‘right answer’.

3. In planning to use this resource it would be useful to explore who would be the best person to facilitate. If being used with an existing team there may be benefits in asking someone a few steps removed from the team (rather than the team leader for example). It might be worth asking your local Organisational Development or Continuing Professional Development teams to assist.

More useful information

NHS Education for Scotland website

Long Term Conditions Alliance Scotland website
www.ltcas.org.uk

My Condition, My terms, My life website
www.myconditionmylife.org

Thistle Foundation website

Disclaimer

A number of treatments are mentioned in the DVD but these are intended as examples only. It is acknowledged that any treatments discussed may not be applicable to all cases and as such are not the intended focus of the resource.
In summary…

Anna’s Story is a team based learning resource…not designed for individual learning.

Anna’s Story requires a facilitated approach…not didactic.

Anna’s Story is about exploring ideas and opportunities which suit the team…not about giving the right answers or predetermined solutions.

Anna’s Story should be used flexibly…it will work best if adapted to suit the participants and local circumstances.

Links to the Knowledge and Skills Framework
(for NHSScotland Staff)

<table>
<thead>
<tr>
<th>Core 1</th>
<th>Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core 2</td>
<td>Personal and people development</td>
</tr>
<tr>
<td>Core 4</td>
<td>Service improvement</td>
</tr>
<tr>
<td>Core 5</td>
<td>Quality</td>
</tr>
<tr>
<td>HWB1, 2 &amp; 4</td>
<td>Health and wellbeing</td>
</tr>
<tr>
<td>IK3</td>
<td>Knowledge and information resources</td>
</tr>
</tbody>
</table>
Introductory activity (optional)

This is an optional introductory activity. It does not have to be used but is a useful way of exploring existing ideas and perspectives before moving on.

Purpose
To explore staff beliefs and values relating to self management.

A values clarification exercise is an active process for making beliefs and values explicit. It is based on the view that it is important to uncover and explore shared and individual views at the outset before moving on to deeper reflection and development of a common vision.

Activity
Ask participants to complete the following sentences;

- I believe the ultimate purpose of self management is…
- I believe this purpose can be achieved by…. 
- I believe that my role in this is…
Facilitators notes
(for introductory activity)

- Encourage contribution of everyone e.g. in small buzz groups or in pairs.
- Capture common ground e.g. use post it notes or similar to capture common themes and ideas.
- Acknowledge any fundamental differences or disagreements and consider exploring these at a later point.
- Remember to make sure participants use ‘I’ statements to encourage them to express their own values and beliefs.
- Encourage people to explain what they mean in their own words, recognising that it can be tempting to use jargon, text book phrases or the latest policy speak.
- Consider how you want to use the information gathered. A values clarification exercise could stop there…in which case it’s main function has been to set the context and highlight values and beliefs as the starting point for the team. Alternatively you might want to consider how the collective information could be used by the team e.g. it may inform strategic direction, could be part of improvement processes, could be developed into a position statement, could be built into the information you provide to the people who use your service.
Extension exercise

*If you want to, you could do more…*

‘*How much of what we believe is reflected in what we do. A match between what we say we believe and what we do is one of the hallmarks of effective teams and organisations*’

Ask the team to consider the above quote and identify ways in which their common values about self management are reflected (or not) in what they do. An idea for facilitating this discussion is provided below;

**Example**

Imagine Sam is going along to his work appraisal/review interview. He has done his bit but has not received any advance feedback. The appraiser puts Sam at ease and lets him know that overall things are going well and he has nothing to worry about. He then drops in a few comments about Sam’s team working and suggests that there are some concerns about his performance in this area. This all comes as a complete surprise to Sam.

What was the impact on Sam having not seen the feedback in advance? No matter how good the skills of the appraiser the emotional impact of receiving the feedback in this manner overrides Sam’s ability to consider it rationally and decide what it really means to him.

If it was you would you not want time to think about it and digest the information? What if Sam was attending an annual clinic for review of his LTC? Many folk would say that sharing the information is part of supporting self management. Is this reflected in what you actually do? For example, do you ensure that the people you see get their results before seeing you? Do you give them enough time to reflect and consider the options before asking them to make decisions? Do you give people time to deal with the emotional impact?

---


Scenes 1 & 2
Introducing Anna and Bess
What the scenes demonstrate

Scenes 1 and 2 introduce us to Anna and her daughter Bess. They give us some background and start to show the impact ill health is having on Anna. They show;

- That Anna has a wide range of roles and relationships
- The key contribution Anna makes to her family
- Anna and Bess’s uncertainty about what might be wrong, not knowing what is happening
- That Anna has been on a considerable ‘journey’ already in trying to understand what is happening to her
- Anna’s own efforts to manage her symptoms

Scenes 1 & 2 Activity

The importance of establishing good partnerships early on is well recognised as a key part of supporting self management. This means giving equal credence to everybody’s perspective: the health professional’s view and the experiences, values and view of the person. This sounds obvious and many health professionals would say that they do this all the time. However it is more complex than it sounds and it is not effortless. Truly hearing the story and comprehending what it means for the person requires effort and skill. Think about meetings at work, how often have you listened without really taking something in or misunderstood the point!

Even in the short introduction to Anna it is clear that she has been on a bit of a journey in terms of her health, both physically and emotionally. It would be easy to listen to her without really understanding what she has experienced and what it means to her.

Questions to ask

1. How could you demonstrate to Anna that you are actively interested in her story and her experiences and what they mean to her?
2. In terms of supporting Anna to self manage why is it important that you continually demonstrate this?
Extension Question for Scenes 1 & 2

‘We may not necessarily condone or approve of everything that the patient tells us but accepting patients without prejudice is fundamental to an empathic approach. It demonstrates our respect for them and this facilitates connecting. Although it may sound straightforward, interacting with people without making prejudicial judgements and treating them in a way that is equal and fair can be a challenge, because we do have tendencies to prefer certain types of people more than others’.³

Not making prejudicial judgements about a person and their lifestyle is complex but is one of the efforts required in forming partnerships for self management. Sometimes negative judgements can be obvious and other times it can be a little bit more insidious e.g. raised eyebrow or glance when person it talking about self medicating, assuming that a person who has not done something is just poorly motivated.

Question to ask

1. When supporting a person to self manage you may be making judgements and decisions, particularly if the focus is on lifestyle or health behaviour. What can you do to support yourself (or others) to not make prejudicial judgements?

Scene 3
Anna’s first video diary entry
What the scene demonstrates

Scene 3 is Anna’s first video diary entry. We hear her talking about the experience of getting a diagnosis and some of her fears and concerns. The scene shows;

- The ‘roller coaster’ experience that can accompany a diagnosis
- Anna’s fears about the impact her illness may have on her relationships
- Anna’s ‘hunger’ for information
- Anna questioning her view of herself and self identity …she says she has ‘stepped over’ a line from being a healthy person to no longer having that view of herself

Scene 3 Activity

Accessing and understanding information is central to enabling people to make choices about self management, their health and their lives. In sharing information with people healthcare professionals can play a crucial role in influencing their ability to understand the information they receive and use it in a way that is meaningful to them. Scene 3 clearly shows that although Anna has some concerns about what she’ll find, she is keen to find out more information about her condition to help her make sense of her situation.

Questions to ask

1. How could you make sure that the self management information that you share with Anna is meaningful for her?
2. How could you check that Anna can use and apply the information that you give her?

---

Extension question for scene 3

Prior to doing this extension question select a number of examples of ways in which information is shared. This could be printed materials such as leaflets, booklets, posters, websites or through opportunities for conversations with other people (preferably choose examples currently available in the participants workplace).

Questions to ask

1. What makes ‘good’ information to support self management? Do the examples used represent good information?

2. Often it can help to get information and support from people in similar situations to your own (peer support). What do you do to enable people to engage in peer support? Could you do more?
Scene 4
Anna’s role in the care of her grandson
What the scene demonstrates

In Scene 4 we see Anna play fighting with her grandson, she is in pain and Bess gets angry with him. This results in a slightly tense conversation between Bess and Anna, which potentially poses a threat to Anna’s role in the care of her grandsons. It shows:

- That Anna’s situation has an impact on the people around her as well
- When we talk about people adjusting to a LTC we need to remember that other people often need to adjust as well, and this can have a major impact on them and the person
- Family roles and expectations can be paramount
- That people face and make decisions about risk every day e.g. Anna’s wish to continue physical play with her energetic grandchild
- That Anna and Bess are weighing up the physical challenges of her caring for her grandsons with the psychosocial benefits on wellbeing and self identity

Scene 4 Activity

Clearly, looking after the grandchildren is part of what makes a ‘good life’ for Anna but it does involve an element of risk taking e.g. it could make her more tired or challenge what she is physically capable of doing on certain days. It might be easy to say she should pace herself, rest when required, and adapt her activity to how she is feeling that day. However this may not fit easily with the reality of her role and aspirations as a grandparent.

Question to ask

‘A good starting point for considering risk can be thinking about how much a particular activity is likely to contribute to – or take away from - the quality of life for the person’

1. How could you promote Anna’s wellbeing without interfering or undermining her enjoyment and key role in caring for her grandchildren?

---

"If it is reasonable, even normal, for us to take some risks, then surely we should acknowledge that this is the same for our patients. Our role is not to offer approval or disapproval, but to offer people information and resources to understand the currently known implications and consequences associated with the behaviours they choose to undertake.”

Whatever term is used, ‘positive risk taking,’ ‘risk management’ or ‘risk enablement’ it is influenced by organisational and whole team commitment, but it is also influenced at an individual worker level.

**Questions to ask**

1. Sometimes it is said that healthcare services tend to focus more on the negative aspects of risk which dissuades people from thinking about the positive aspects, such as the opportunity for growth or achievement, satisfaction in accepting a challenge or positive impact of helping others. In what ways does this apply or not apply to your own team or service? What impact does it have?

2. How could you influence the development of a climate that promotes safety and supports risk enablement?

---

Scene 5
Anna's second video diary entry
What the scene demonstrates

Scene 5 is Anna’s second video diary entry. The scene demonstrates:

- Anna’s emotional response to her situation
- The feeling of ‘losing control’ that is often part of the experience of living with a LTC
- The tensions Anna feels about knowing what she should be doing but not actually doing it
- The impact of the condition across Anna’s whole life, including her sexual relationship with her partner Dave
- How some information/advice given has made assumptions about Anna and been unintentionally unhelpful
Scene 5 Activity

The literature about self management says that a key task for service providers is to support a person’s self efficacy (in its simplest form this means a person’s self confidence to use self management skills successfully). In scene 3 Anna talks about how she feels she has ‘stepped over’ an imaginary line between being a healthy person and a not healthy person and in this scene she talks about her sense of control, her relationship and, to some degree, her whole sense of who she is. Living with a LTC means living with the consequences of the condition itself and sometimes with the consequences of the treatments offered. Supporting self management can take many forms but it needs to include support to develop both practical and emotional coping skills. This can include support to address things such as self identity, self resourcefulness, coping with emotions, self confidence and altered outlook/perspectives.

We can support self confidence or self efficacy through affirming, praising, congratulating, endorsing, supporting the person to refine techniques and gain mastery over self management behaviours and actions and by offering opportunities for physiological feedback.

Question to ask

1. In supporting self management what do you currently do to address a person’s self confidence or self efficacy? What tools or resources do you use? What more could you do?

Extension question for scene 5

In the scene Anna recounts being described as a person who likes to be ‘in control’. There are a number of phrases within the self management literature which link self management to the notion of being in control e.g. self management puts the ‘person in charge’ or puts the person ‘in the driving seat’ etc. Some people are comfortable with the idea of being in control and others are less so.

Question to ask

1 How do you deal with this in your everyday practice?

“If I have the belief that I can do it, I shall surely acquire the capacity to do it even if I may not have it at the beginning.” attributed to Mahatma Gandhi
Scene 6
Bess and Anna in the kitchen
What the scene demonstrates

Scene 6 shows Bess and Anna in the kitchen. Bess has been made aware of an incident where the neighbour found Anna upset and unwell on the stairs. The scene shows;

- Some tension between Anna and Bess with them both feeling uncertain of the new dynamic between them
- Bess feeling a bit bewildered and ‘shut out’ by Anna

Scene 6 Activity

It is important not to underestimate the role other people play in supporting a person with a LTC to self manage. After all, the person may only see a healthcare provider for a few hours a year, the rest of the time they manage themselves or with the support of other people. Bess is a key person in Anna’s life who could offer considerable support for self management. But the clip shows that adjusting to the changing nature of relationships are not necessarily automatic and can result in an emotional response from all concerned.

Questions to ask

1. How would you explore Bess’s potential role in supporting Anna to self manage?
2. What strategies could be used to include Bess in supporting Anna to self manage?

---

Extension Question for scene 6

The systems and processes used by your team can actively support the engagement of family and carers, or they can (possibly unintentionally) discourage it. Ways to give positive messages include: asking questions about possible role for family, self management plans with a clear role/task for families, carer perspective included in goals setting, offering opportunity for significant others to attend appointments etc.

Question to ask

1. What could you do to create the expectation that, where appropriate, family and carers are actively involved in supporting the person to self manage?
Scene 7

Anna: One year on
What the scene demonstrates

Scene 7 is an interview with Anna one year on from the point we were first introduced to her. It demonstrates:

- Anna being supported by a worker whose approach is different, in that they value and capitalise on the skills and experiences she has.
- Anna describes this approach as one where the worker listened and asked some important questions. This was different from the usual approach which she experienced as ‘lessoning rather than helping’.
- Anna having a positive experience of weighing up and making choices about risk.
- The value Anna places on being treated as a whole person not just a condition.
- That Anna’s confidence has grown and that she is taking more control over her life.
Scene 7 Activity

At the heart of supporting self management is the need to uncover and build on peoples existing capabilities and strengths, and to actively support them to put these to use. We usually have no problem identifying deficits and perceived problems, but find it harder to identify strengths. Focusing on problems and limitations can be disheartening. When someone has been in contact with health services over a period of time their sense of self (image and identity) can become dominated by the experience of illness, the losses which come with it and the support and treatment required. Anna identified that the worker who had a positive impact on her asked about different things, not just problems. She highlighted and used Anna's experience and knowledge from being a teacher.

Facilitator notes: This is a short exercise using the following three questions. Ask participants to do the first question individually (rather than in groups/pairs) and tell participants not to pick something too personal or painful.

Questions to ask

1. Think of something challenging that you have had to deal with recently (e.g. re-establishing yourself in new job, health issues, conflicts at work). What strengths or resources did you use to deal with this situation?

2. What was easy or difficult about identifying your own strengths or resources (generally speaking, it can be quite hard to recognise and name our own strengths)?

3. What approaches or styles of questioning could you use to help people to identify their strengths and resources? For example, ‘what (or who) can I tap into to help me to deal with the issue’?

Facilitator notes: This section is mainly asking participants to think about ‘assets’. Assets are recognised as being important in creating and maintaining good health for individuals and communities. When discussing question three it may be helpful to offer the following description of assets;

- personal things such as your experience, your life roles, your knowledge, your confidence, your motivation, your faith or spirituality, your determination and resilience.
- other people and community, such as neighbours, family, friends, clubs, groups, sports activities and perhaps pets.
- wider societal things, such as access to internet, good housing, having a job to go to and accessible transport.
Extension Question for scene 7

As with some of the other ideas described in this resource it can be quite easy to say ‘but we already do that’ or ‘we already focus on strengths’. In some instances this may be true; in others it may be a view held by some individuals but it is not reflected in the culture or the way the service is run.

Questions to ask

1. If you were to read the records or assessments for one or two people what message would they convey about that person?
   - In what ways, if any, would they demonstrate that your team/service values and focuses on the capacity, skills, knowledge and connections/relationships of the person?
   - Would you be able to describe that person’s strengths, connections, role in the community, interests, activities, contribution to others etc from what you have read?
   - What impact do you imagine it might have if these records focused on the positive capacity and connections of individuals and communities?

2. You could consider checking out your thoughts on this back at your workplace to see how they are reflected in reality. To do this briefly read two or three of the file notes, patient records, case notes, assessment forms (or any equivalent documentation) routinely done by your team/service and answer the questions again. Were your initial thoughts correct?
Scene 8

Reflection
Scene 8 is the concluding scene and is an interview with Anna and her daughter Bess. It is the ‘wrap up’ scene intended to complete the story. It shows Anna and Bess reflecting on their journey, some of the challenges they have encountered and how they have dealt with them. They have found ways of making a good life.

What next?

With the participants consider how all of the information and discussions that have taken place as you have facilitated this resource could be captured and used by the team. This could take a number of forms ranging from little easy to do changes to more ambitious projects. For example;

- You could ask each participant to make a personal commitment to something such as asking a new question in routine appointments.

- You could seek agreement about making a small change such as altering assessment forms or changes to the physical environment.

- You could develop an action plan for meeting any further learning or information needs which have come up while discussing Anna’s story.

- For some ideas it might be helpful to consider a Plan Do Study Act$^9$ cycle at some stage.

---
