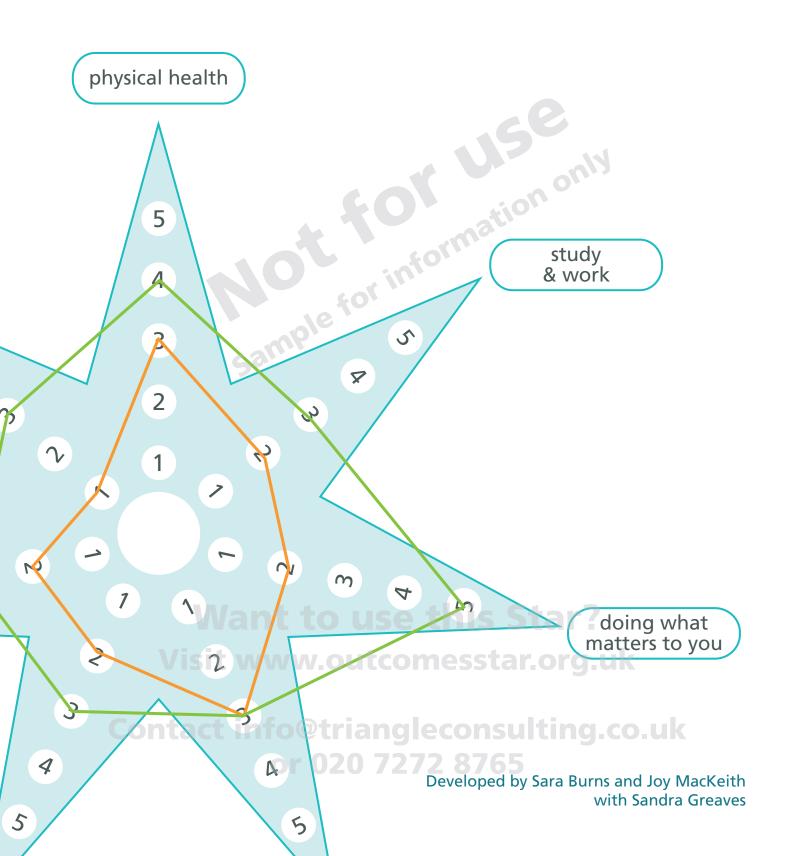




Support Star (Young People)™

The Outcomes Star for young people facing serious illness



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Triangle Consulting Social Enterprise Ltd The Dock Hub Wilbury Villas Hove BN3 6AH United Kingdom

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Authors

Sara Burns and Joy MacKeith with Sandra Greaves Triangle Consulting Social Enterprise Ltd www.outcomesstar.org.uk

Edited by Jellymould

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Based on an original design by Jellymould www.jellymould.net

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Please contact **info@triangleconsulting.co.uk** to enquire about buying a licence and training.

Licences are also available for those wishing to translate the document into other languages.

The Outcomes Star™

This Star is part of a family of Outcomes Star tools. Each tool includes a Star Chart, User Guide or Quiz and guidance on implementation and some have visual and other resources. For other versions of the Outcomes Star, good practice and further information see www.outcomesstar.org.uk.

Acknowledgements

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We would particularly like to thank CLIC Sargent for their contribution to this version of the Star.

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Introduction to the Support Star (Young People)™

The Support Star (Young People) is a tool to help young people facing serious illness to talk about the impact of their illness on different aspects of their life and identify any support they may need. It is a version of the Outcomes Star, a suite of tools for supporting and measuring change when working with people. There is also a version of the Support Star for parents of younger children.

Outcome areas

The Support Star (Young People) covers seven areas of life:

- 1. Physical health
- 2. Study and work
- 3. Doing what matters to you
- 4. Money
- 5. Friends and relationships
- 6. Home and family
- 7. Emotional well-being.

The Journey of Change

ung n The Journey of Change describes the process young people go through in responding to their illness and in navigating through the impact it has on different aspects of life. Everyone's experience is different, but the pattern of change is often similar. Moving along the Journey of Change isn't dependent on your illness or how treatment progresses.

The Journey of Change has five stages:

- 1. Not able to respond
- 2. Taking it in
- 3. Trying to respond
- 4. Finding a way through
- 5. Managing well.

These stages are colour-coded as well as numbered. The Journey of Change is described in detail on the next page.

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Detailed Journey of Change

1. Not able to respond

At this stage of the journey you are **not able to respond**, whether you have just been diagnosed, are in treatment or have finished treatment. Some people describe this stage as feeling as if they are in a bubble – perhaps you are in crisis or reeling with the impact of the illness.

You may feel shocked, confused, frightened, angry, overwhelmed, numb or withdrawn, or perhaps are not aware of your feelings. There may be immediate actions or decisions to carry out, but you have not yet taken in what is happening or any implications beyond the immediate crisis. If support is offered you can't really engage with it.

2. Taking it in

At this stage you are **taking in** what your condition is and what it means for you and your family. Whether you are recently diagnosed, in treatment or have finished treatment, you are taking in the implications for you and the changes you may need to make in order to respond to what is required now

You may feel angry, anxious or overwhelmed, or driven to understand as much as possible. Perhaps you are asking lots of questions, but you don't yet know how to manage the implications and may feel unable to gain control or have difficulty in making decisions and are not yet considering long-term plans or addressing major change.

3. Trying to respond

At this stage you understand what is needed and are **trying to respond**. Whether you are recently diagnosed, in treatment or have finished treatment, you are immersed in trying to sort things out and to gain a sense of control of the situation and make plans, but it's hard and you have not yet found a way through.

You may be trying to get financial help, making contact with support groups or trying to find other sources of practical or emotional support. Perhaps it feels daunting, you experience constant setbacks or you feel as if you are floundering and are not yet able to manage in this new reality.

4. Finding a way through

At this stage you are **finding a way through**. Whether you are just diagnosed, in treatment or have finished treatment, you are learning to manage, may have made some big decisions and are finding strategies to deal with some of the limitations and requirements of your situation

You may have some practical and emotional support in place, but there are still issues you need to sort out. You still find it hard to respond to some difficulties or when there is bad news about your illness, treatment or prognosis, but you are developing a measure of resilience. Perhaps you are starting to understand how life is now for you and those around you.

5. Managing well

At this stage you are **managing well**. Whether you are recently diagnosed, have recovered, have ongoing side effects, are still in treatment or your condition is beyond treatment, things are as good as they can be under the circumstances and you and others are doing all you can.

You mostly accept how things are for you now, live as well as you can and feel some choice and control in your life, so you are able to look ahead and make plans. Perhaps the experience has changed you and you feel wiser or now have different priorities. You have developed some resilience and can mostly respond to whatever you face with the help of family, friends, support services or professionals.

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It's not just down to you

The Support Star (Young People) focuses primarily on the things that you and those supporting you can do to minimise the impact on your diagnosis. However, it's important to recognise that there will be conditions which will affect you but are largely or entirely beyond your control. The impact of treatment and prognosis are the most obvious, but there may also be issues around where you are living, work, study, money or access to services. Using the Star may help you identify those external factors as well as the things you can change.

How does it work?

For each of the seven areas, there is a scale, which follows the Journey of Change.

To complete the Star, look at each of the seven scales one by one and talk them over with your worker. Together you can agree where you are in each area. Then mark the number on the Star Chart and connect the points to create a picture of how things are now, the areas that are working well and the ones that are causing difficulties.

This will help you and your worker to agree on how to support you, wherever you are in the formation treatment journey.

Your own personal journey

You and your worker can come back to the Star at a later point in time, look at the scales again, agree where you are, and plot a new shape on the Star Chart. You will see where you have come from and how things have changed for you and this can be a good basis for seeing where support could be helpful. It may also help to put the ups and downs of a single week into a bigger picture.

It also helps us to get an idea of whether the service is giving the right support.

Support Star (Young People)[™] resources

- 1. Support Star (Young People) Chart, notes and Action Plan for use with young people
- 2. This User Guide, containing a short version of the scales and the detailed scales on facing pages and the detailed Journey of Change
- 3. Guidance for Workers
- 4. Optional short illustrated scales for use with young people
- 5. An Implementation Guide, for those in a management role
- 6. Star Online for on-screen completion and generating reports.

For background and further information see www.outcomesstar.org.uk.

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1 Physical health

- Medication
- Treatment
- Fertility and other side effects
- Healthy lifestyle

5 Managing well

I look after my health and manage any side effects well enough

4 Finding a way through

I mostly look after my health and manage any side effects but need to make some changes

this Star?

3 Trying to respond

I'm trying to have a healthier lifestyle and manage any side effects but it's hard

2 Taking it in

I'm finding out how to look after my health with this condition

1 Not able to respond

I don't take care of my health even though I have a serious illness

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1 Physical health (detail)

This scale is about how well you are looking after your health at the moment, not whether your health is good or not. It includes managing any physical side effects of treatment, eating healthy food, drinking sensibly, not smoking, taking exercise and getting enough sleep. It is also about your medication and other treatment – making sure this is right for you and following the right treatment programme once you have identified it.

5 Managing well

I look after my health and manage any side effects well enough

- You follow treatment advice and take any medication on your own if you are at home. You are alert to symptoms and report anything unusual straight away
- If you have side effects, you have effective strategies to minimise their impact on your life, such as managing pain or limited energy. If your fertility is affected, you have done what you can and come to terms with how things are
- You lead as healthy a lifestyle as you can. If you are well, you eat healthily, take exercise, get enough sleep, drink alcohol within safe limits or not at all and don't misuse drugs

4 Finding a way through

I mostly look after my health and manage any side effects but need to make some changes

- You mostly follow treatment advice, remember medication, look out for symptoms or changes and report anything unusual
- You are learning to manage and cope with any side effects you experience, such as tiredness or pain. If loss of fertility is a risk, you are doing what you can to give you choices in the future
- If you are well, you mostly have a healthy enough lifestyle, but there are a few problem areas

3 Trying to respond

I'm trying to have a healthier lifestyle and manage any side effects but it's hard

- You are trying to follow treatment advice but may find it hard to stick to regularly. Perhaps there is more that can be done to make the treatment easier for you
- You are trying to manage any side effects or work around them and get on with your life. This may include looking into fertility options
- You are taking steps to make your lifestyle healthier, such as eating more healthily or cutting down on alcohol or drugs but it's hard to establish new habits, especially if you feel unwell

2 Taking it in

I'm finding out how to look after my health with this condition

- You are learning about your medication and the symptoms or reactions you need to look out for during your treatment
- You are finding out about any side effects, how long they might last, what else might happen and how other people cope with them
- You are realising you need to look after your health better now that you are ill, but have not taken action yet. There may be practical barriers to healthy choices, especially in hospital, or you may be too ill or tired just now to do much to improve things

Not able to respond

I don't take care of my health even though I have a serious illness

- You may not stick to your medication or other medical treatment. Perhaps you don't understand the consequences of not following the treatment and/or are struggling with the side effects. If your fertility may be affected, you can't take this in at the moment
- You don't have a healthy enough lifestyle. You don't eat healthily, take the exercise you need, sleep enough and/or are drinking too much or taking harmful drugs. Perhaps this didn't matter much before, but it does now
- You can't face thinking about this or don't want to discuss it



2 Study and work

- Education
- Work
- Training
- Volunteering
- Goals for the future

5 Managing well

I'm in education, work or training or on a break but clear about my plans

4 Finding a way through

I'm finding a way to manage in relation to work, study or other plans but am not there yet

3 Trying to respond

I'm trying to sort things out in relation to work, study or other plans, but it's hard

2 Taking it in

I'm taking in what my condition means for my work, study or plans

1 Not able to respond

I'm not able to study or work at the moment. I can't do anything about it just now

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2 Study and work (detail)

This scale is about education, work or training – carrying on if possible with what you were doing before you became ill, whether this was school, college, university or work, or making new plans. If you are having a break in study, work or training because of your condition, or don't think you can return to it, this scale is an opportunity to look at sorting things out with your college or employer and your priorities for the future.

5 Managing well

I'm in education, work or training or on a break but clear about my plans

- If you are at school or college or in work or training, you are able to keep up with the work and cope with any issues you find there
- If you are on a break, you have sorted things out with your college or employer and have plans in place for your return
- If you had to change your plans, you have accepted this and are doing what you can. You may be doing voluntary work

4 Finding a way through

I'm finding a way to manage in relation to work, study or other plans but am not there yet

- You are managing to study, work, volunteer or pursue other plans, perhaps part-time, or to sort out taking a break, though there are still some obstacles you need to overcome or things you feel you could do
- You may be acquiring skills or experience to allow you to study or work in the future
- You have the support you need and are making progress with what you want or need to do, though there are a few important things you still want to sort out

3 Trying to respond

I'm trying to sort things out in relation to work, study or other plans, but it's hard

- If you have recently been diagnosed, feel too ill to study or work or there is too much happening with treatment, you may be liaising with your college or employer about a break, but it seems hard to make it happen
- If you are recovering, you may be trying to go back to what you were doing before you got ill, applying for places or restarting education, work or training, but you are facing setbacks

2 Taking it in

I'm taking in what my condition means for my work, study or plans

- You are working out what is possible for you now and may be recognising that your immediate work, study or plans have to go on hold, for example attending college
- You may be finding out about taking or retaking courses, studying part-time, volunteering, training, or different things you might be able to do, but you have not yet taken action

Not able to respond

I'm not able to study or work at the moment. I can't do anything about it just now

- Perhaps you have a job or college place but are not able to keep up with it, don't yet know what the implications of your condition are and/or need to take a break but have not yet sorted things out with your college or employer or have no plans to return
- Perhaps you were not in school or college, work or training, had no plans before you fell ill or had other plans you now can't follow
- You may feel stuck, don't know what to do, have more pressing priorities or don't believe you can have goals just now. Whatever the reason, you don't talk about this or engage with support if it's offered



3 Doing what matters to you

- Activities that make life meaningful
- Social life
- Enjoyment
- Feeling like yourself

Managing well

I'm able to do enough of what is important to me now

Finding a way through

I'm finding ways to do some tion only of what matters to me

Trying to respond

I'm trying to do what matters to me but it's difficult

Taking it in

I'm taking in what my condition means for what I can and can't do

Not able to respond

I can't do the things that matter to me and make life tcomesstar.org.uk meaningful. I can't think about this now

this Star?

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3 Doing what matters to you (detail)

This scale is about being able to do things that you value and enjoy, that make life meaningful and/or help you to still feel like you. This may be taking part in social events or activities, having fun or managing to do the big or small things you want to achieve in your life. It is about actively choosing what you want to do in your new circumstances and having any support you need to make it happen.

5 Managing well

I'm able to do enough of what is important to me now

- You are able to do enough things that give you pleasure, make life meaningful or enhance your quality of life
- You are realistic, accept what you can do now and in the near future and are managing to put plans into action
- You feel you have some choice and control over what you do with your time
- If your condition is life-limiting, you know what you want to achieve with the time you have and you and others are making it happen

4 Finding a way through

I'm finding ways to do some of what matters to me

- You are finding ways to do at least some things that are important to you or make you feel like you and developing a realistic sense of what you can achieve for now. This may be similar to before you were ill or you may find your priorities have changed
- You are finding ways to feel in control in some areas and some things you want to do are clear and achievable but there is more to work out

3 Trying to respond

I'm trying to do what matters to me but it's difficult

- You are trying to work out how to do things that mattered to you before you were ill, such as taking part in social activities, having fun, or achieving big or small ambitions, but your condition keeps changing or it's hard to deal with the limitations you are facing
- You may be considering other possibilities or finding support to help you achieve what you want
- You are trying out different ways to do what matters to you or to realise your ambitions, but may face a lot of obstacles

2 Taking it in

I'm taking in what my condition means for what I can and can't do

- You are finding out the implications of your condition for things that are important to you now and/or any long-term implications such as possible loss of mobility or other function
- You may be recognising that immediate plans will have to go on hold
- You may be talking to someone about this or getting in touch with others in the same situation

Not able to respond

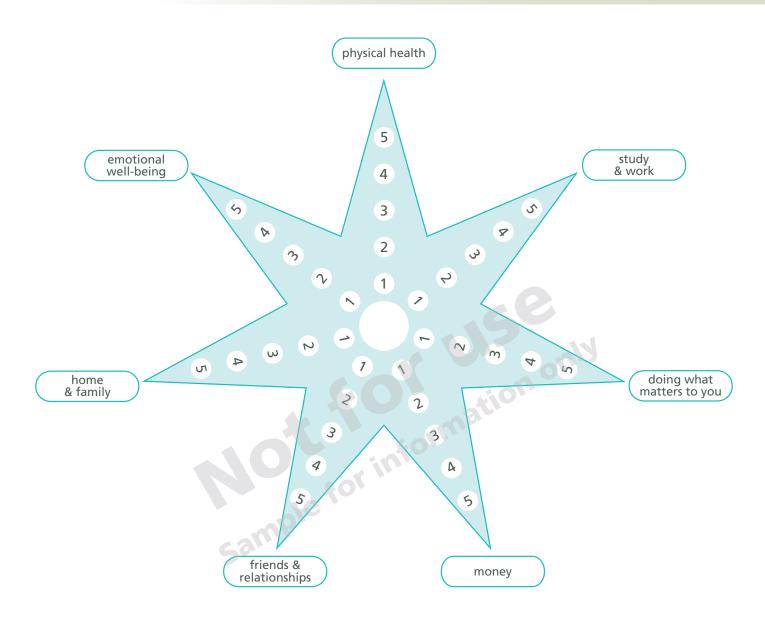
I can't do the things that matter to me and make life meaningful. I can't think about this now

- Your condition has thrown into question how you see your life now
- Perhaps you are now not able to do things that are important to you, or your immediate plans for social or other activities are coming apart and you don't know what to do
- You can't face thinking about this or you don't want to talk about it

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The Support Star (Young People) $^{\text{m}}$ is a version of the Outcomes Star $^{\text{m}}$, a family of tools developed by Triangle for supporting and measuring change when working with people.

This Star is one of a growing family

See our website for:

- Versions tailored to different people, settings and sectors
- The evidence base that supports the Star
- Testimonials and case studies from Star users

www.outcomesstar.org.uk

How to use the Outcomes Star

- Sign up for Star licences including the option to use our Star Online web app
- Ensure all members of staff attend Star training and explore specialist courses
- Access Star materials, other tools and ongoing support from Triangle

Go to www.staronline.org.uk for a free 30-day demo