



# Support Star (Parents)™

The Outcomes Star for parents of children facing serious illness

looking after  
your child

managing  
practicalities

Not for use  
sample for information only

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Contact [info@triangleconsulting.co.uk](mailto:info@triangleconsulting.co.uk)

or 020 7272 8765

Developed by Sara Burns and Joy MacKeith  
with Sandra Greaves of Triangle  
Consulting Social Enterprise

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Wilbury Villas  
Hove  
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United Kingdom

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## Authors

Sara Burns and Joy MacKeith  
with Sandra Greaves  
Triangle Consulting Social Enterprise Ltd  
[www.outcomesstar.org.uk](http://www.outcomesstar.org.uk)

Edited by Jellymould

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[www.jellymould.net](http://www.jellymould.net)

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Please contact [info@triangleconsulting.co.uk](mailto: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](http://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 (Parents)<sup>™</sup>

The Support Star (Parents<sup>1</sup>) is a tool to support parents of children facing serious illness. It helps parents to talk about the areas of life that may be affected by their child's illness and think about what 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 a separate version of the Support Star for young people facing serious illness.

## Outcome areas

The Support Star (Parents) covers six areas of life:

1. Looking after your child
2. Managing practicalities
3. Money
4. Your child's education
5. Being a family
6. Your emotional well-being.

## The Journey of Change

The Journey of Change describes the process parents go through in responding to their child's illness and in navigating through the impact it has on different aspects of life. Everyone's experience will be different, but the pattern of change is often similar. Moving along the Journey of Change isn't dependent on your child's 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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1 Throughout the documents 'parent' is used and can include carers or others in a parenting role.

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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 your child has recently been diagnosed with a serious illness, is in treatment or has finished treatment. Perhaps you are in crisis or just don't know what to think, feel or do: some people describe this stage as feeling as if they are in a bubble, or are reeling with the impact.

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 child's condition means. Perhaps they have recently been diagnosed or they are in treatment and you are only now able to take in the impact. You are considering the implications for you as a family and the adjustments you may need to make.

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. Although immediate decisions and actions need to happen, you are not yet considering long-term plans or addressing major change.

## 3. Trying to respond

At this stage you understand the choices and changes you need to make, wherever your child is in their treatment, and are **trying to respond**. You are immersed in trying to sort things out and trying 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 take practical steps such as applying for any financial help you are entitled to or making contact with a support group. Perhaps things feel daunting, you experience constant setbacks or you feel as if you are not yet able to find a way through.

## 4. Finding a way through

At this stage you are **finding a way through**. Whether your child has just been diagnosed, is in treatment or has finished treatment, you are learning to manage, have made some big decisions and are finding ways 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 a few issues you need to sort out. You find it hard to respond to some difficulties or to bad news about your child's illness, treatment or prognosis, but you are developing a measure of resilience. Perhaps you are starting to experience a more stable, if different, life for you and your family.

## 5. Managing well

At this stage you are **managing well**, whether your child is recently diagnosed, has recovered, has ongoing side effects, is still in treatment or you have been told that their condition is beyond treatment. Things are as good as they can be under the circumstances.

You have acquired understanding of how to cope and regained some balance and a degree of normality in your life, though this may be very different from how it was before. You live as well as you can and 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 cope with whatever is needed with the help of family, friends, support services or professionals.

# It's not just down to you

The Support Star (Parents) focuses primarily on the things that you and those supporting you can do to minimise the impact on you, your sick child and your family. However, it's important to recognise that there will be conditions which will affect you and your family 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 housing, work, 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 six areas, there is a scale, which follows the Journey of Change.

To complete the Star, look at each of the six 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 your child is on the treatment journey.

## Your journey as a family

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 thinking about 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 enables us to get an idea of whether the service is giving the right support.

## Support Star (Parents)<sup>™</sup> resources

1. Support Star (Parents) Chart, notes and Action Plan for use with parents
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 parents
5. Star Online for on-screen completion and generating reports.

**Want to use this Star?**

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# 1 Looking after your child

- *Practical care and emotional support*
- *Helping your child to cope with their illness*

## 5 Managing well

I'm confident I can look after my sick child and support them emotionally through this

## 4 Finding a way through

I'm managing to look after my child in most ways but am not there yet

## 3 Trying to respond

I'm trying to care for my sick child and help them cope emotionally, but it's hard

## 2 Taking it in

I'm finding out what I need to do to look after my child physically and/or emotionally

## 1 Not able to respond

I'm not able to look after my sick child or help them through this

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# 1 Looking after your child (detail)

This scale is about your role as a parent in caring for your child through their illness and helping them cope with the ups and downs of treatment and beyond. It includes understanding your child's condition, being able to spot changes, having the skills and equipment you need and communicating with medical professionals. It is also about you and others providing emotional support, encouragement, warmth and connection.

## 5 Managing well

### I'm confident I can look after my sick child and support them emotionally through this

- You understand your child's condition, have the main skills and equipment you need and feel comfortable with the tasks involved. You communicate well with medical professionals
- You support your child through ups and downs and help them become more resilient
- You and perhaps others are able to give them enough attention, encouragement, warmth and reassurance but also allow them the independence they need, depending on their age

## 4 Finding a way through

### I'm managing to look after my child in most ways but am not there yet

- You are mostly able to do what is needed to care for your child physically but may not be confident in some aspects, such as advocating for your child with medical professionals
- You may be finding ways to build your child's resilience, but there is more you could do
- You are finding ways to give your child emotional support, perhaps with help from a professional or support group, but there are still some problem areas

## 3 Trying to respond

### I'm trying to care for my sick child and help them cope emotionally, but it's hard

- You are trying to do what is needed to care for your child physically but may not feel you have the confidence or skills
- You are trying to give your child the emotional support they need and to offer encouragement, warmth and reassurance, but it's hard and you may not have found the right approach yet. You may be trying to get professional support for them
- You may be trying to give your child space to talk through their fears but find it hard to hear without feeling fearful or sad yourself

## 2 Taking it in

### I'm finding out what I need to do to look after my child physically and/or emotionally

- You are learning about your role in caring for your child, though you are not yet able to do everything that is needed and may worry about missing symptoms or changes. You may be researching treatment, side effects, food or other areas
- You have some understanding of what your child is going through but don't know whether you can help them cope emotionally just now
- You may be talking to someone about this or getting in touch with others in the same situation

## 1 Not able to respond

### I'm not able to look after my sick child or help them through this

- You don't feel able to support your child just now – perhaps you feel too numb, anxious or fearful yourself or are very worried about how they will cope emotionally
- Perhaps you are afraid of making a mistake in terms of practical caring or spotting symptoms, or you don't have space to consider the emotional aspect of what is happening
- You can't face talking about this just now or can't take in what people are saying

## 2 Managing practicalities

- *Appointments*
- *Travel*
- *Work*
- *Childcare*
- *A suitable home*
- *Running your home*

### 5 Managing well

We are managing well enough on a practical level as a family

### 4 Finding a way through

We are learning how to manage on a practical level but we have a way to go yet

### 3 Trying to respond

I'm trying to make changes so we can manage better, but it's hard

### 2 Taking it in

I'm finding out what this means in practical terms but don't know how we will manage

### 1 Not able to respond

I don't know how we will manage the practicalities and am struggling from day to day



## 2 Managing practicalities (detail)

This scale is about coping on a practical level with things like home, work, hospital, family and other areas of life when your child has a serious illness. It includes getting to hospital appointments, dealing with travel and accommodation, making arrangements with work, covering childcare if needed, adapting your home, and other aspects of running things day to day.

### 5 Managing well

#### **We are managing well enough on a practical level as a family**

- You are coping well enough with practical issues resulting from your child's condition and have enough support to manage, including childcare if needed. Things may not be ideal but you accept how they are
- Your home is suitable for your child, with any necessary aids and adaptations. If you need to be close to the hospital you have an effective arrangement for accommodation
- You have sorted out an effective work situation in your family that gives you time to look after your child, whether this means flexible hours or one or both parents not working

### 4 Finding a way through

#### **We are learning how to manage on a practical level but we have a way to go yet**

- You are finding ways round most practical problems and have some of the support you need to cope, though there are still some issues to resolve
- If your home was unsuitable for your child, it now mostly works but may need minor adaptations. If you live far from the hospital you have somewhere to stay for now
- You have mostly sorted out your family's work situation so you have the time to look after your child, though the current solution may be temporary or there are still difficulties
- You are mostly managing the day-to-day running of the house, though it may not be to the standard you would like

### 3 Trying to respond

#### **I'm trying to make changes so we can manage better, but it's hard**

- You are trying to address practicalities, make decisions and plan ahead but there are a lot of obstacles
- If your home is unsuitable for your child, you are trying to organise adaptations. If you need accommodation near hospital, you are trying to find something suitable
- You may be trying to negotiate more flexible hours or other changes at work, sort out childcare or get longer-term support in place
- You may be trying to keep up with shopping, cooking or housework but often can't juggle all the competing demands

### 2 Taking it in

#### **I'm finding out what this means in practical terms but don't know how we will manage**

- You are taking in the practical implications of your child's condition but don't yet know how to solve the main problems and may be ignoring smaller issues
- You may be finding out how employers will react, researching accommodation, childcare or other issues, or talking to someone about these, but have not yet made key decisions

### 1 Not able to respond

#### **I don't know how we will manage the practicalities and am struggling from day to day**

- Your life and family routines have been turned upside down. Perhaps you spend large amounts of time in hospital or travelling and don't know how you will manage
- Perhaps you don't yet have manageable solutions for urgent practical problems such as childcare or cover at work
- If support is offered, you can't engage with it, but may let people take action on your behalf

# 3 Money

- *Money issues related to your child's condition*
- *Earnings*
- *Benefits*
- *Grants*
- *Debts*

## 5 Managing well

We are managing financially or things are no worse than before my child got ill

## 4 Finding a way through

I'm finding a way through the extra money worries but am not there yet

## 3 Trying to respond

I'm trying to do something about the impact on our finances but it's difficult

## 2 Taking it in

I'm taking in what my child's condition might mean for our finances

## 1 Not able to respond

I'm not able to think about money right now and/or don't know how we will cope financially

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# 3 Money (detail)

This scale is about tackling financial difficulties resulting from your child's illness and being able to cover extra costs of things like travel, accommodation and treatment. It covers sorting your finances out as needed, including earnings, benefits and grants, and making any adjustments needed to pay bills or debts and to manage on your income. It also includes getting any support you need to help you to cope with money worries.

## 5 Managing well

### **We are managing financially or things are no worse than before my child got ill**

- If your child's illness has impacted on your family financially, for example if one or both parents have had to stop work for a while, you have found ways to manage well enough
- Things may not be easy but you and others have done all you can and are able to cover any extra costs arising from your child's condition
- You are receiving any financial support available to you, such as benefits, grants or help with travel or accommodation

## 4 Finding a way through

### **I'm finding a way through the extra money worries but am not there yet**

- You are finding a way to manage financially in your new circumstances, adjusting your priorities if necessary. If you were worried about money, this is easing
- If you or your partner were trying to change working hours or job, you have mostly sorted this out, though may have less income
- You have mostly applied for financial support and/or renegotiated repayments as needed but perhaps there is still more to sort out or things keep changing

## 3 Trying to respond

### **I'm trying to do something about the impact on our finances but it's difficult**

- You may be trying to get control of your finances, to budget or to plan ahead but it's hard to do. Perhaps the extra costs arising from your child being ill keep growing
- You may be trying to keep a job or find an alternative that you can manage around your child's illness
- You may be applying for benefits, grants or other funds, trying to defer or rearrange debt payments

## 2 Taking it in

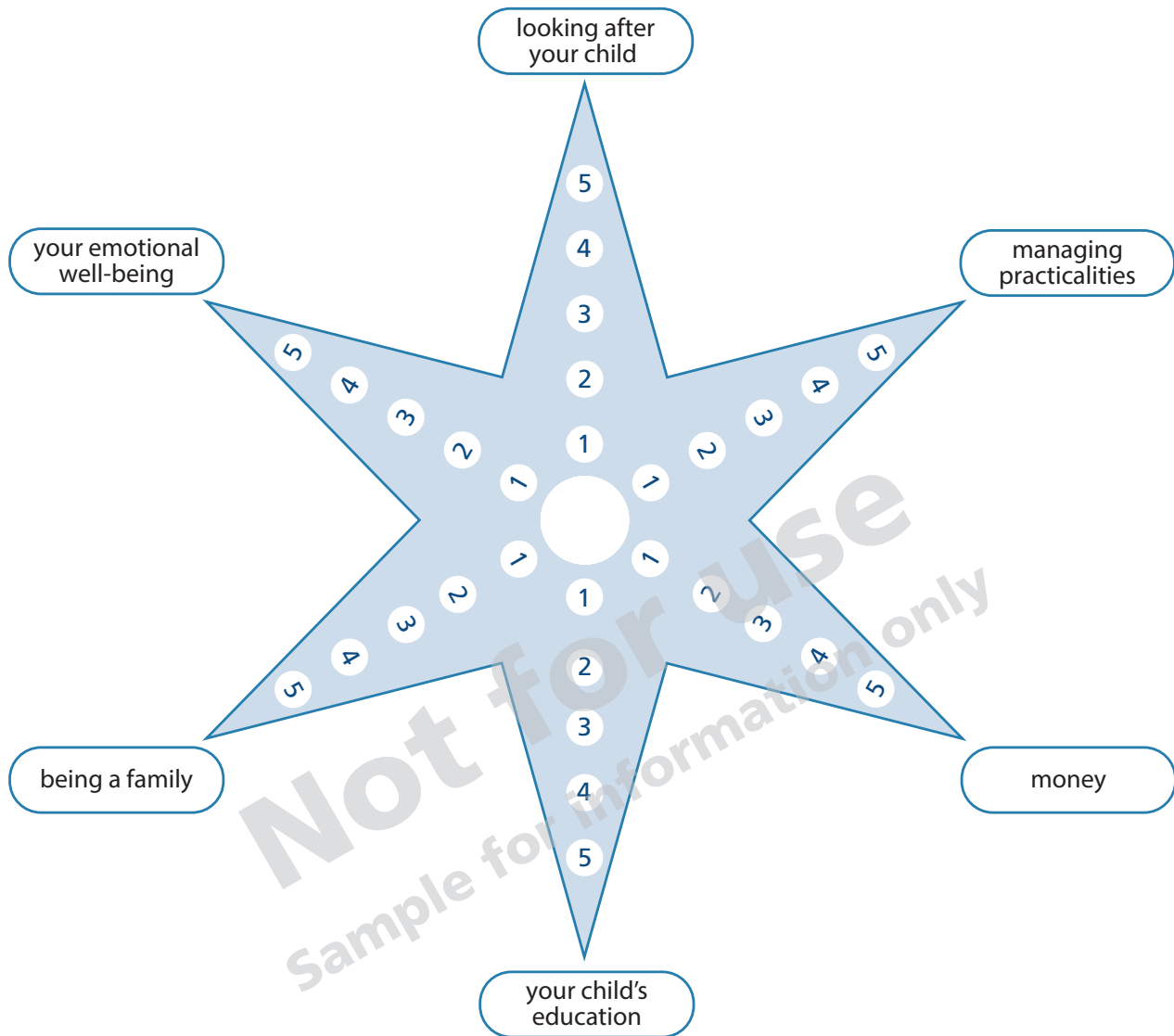
### **I'm taking in what my child's condition might mean for our finances**

- You are beginning to take in the impact of your child's condition on your family's finances and this may add to your anxiety
- Perhaps you are realising that you or your partner have to change your working hours or give up your job
- You may be getting advice about benefits, grants, loans, or employment rights, but don't feel able to sort things out for yourself. Perhaps it's just too low a priority with everything else that's happening

## 1 Not able to respond

### **I'm not able to think about money right now and/or don't know how we will cope financially**

- You may be losing earnings to deal with the crisis, or you may feel no change yet but have not taken in what the impact could be on your finances in the future
- Perhaps you are having to pay for travel, accommodation or other unexpected costs
- If support is offered, you can't engage with it, but may let people take action on your behalf to apply for benefits or grants, access support or negotiate with your employer



The Support Star (Parents)™ is a version of the Outcomes Star™, 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](http://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](http://www.staronline.org.uk) for a free 30-day demo