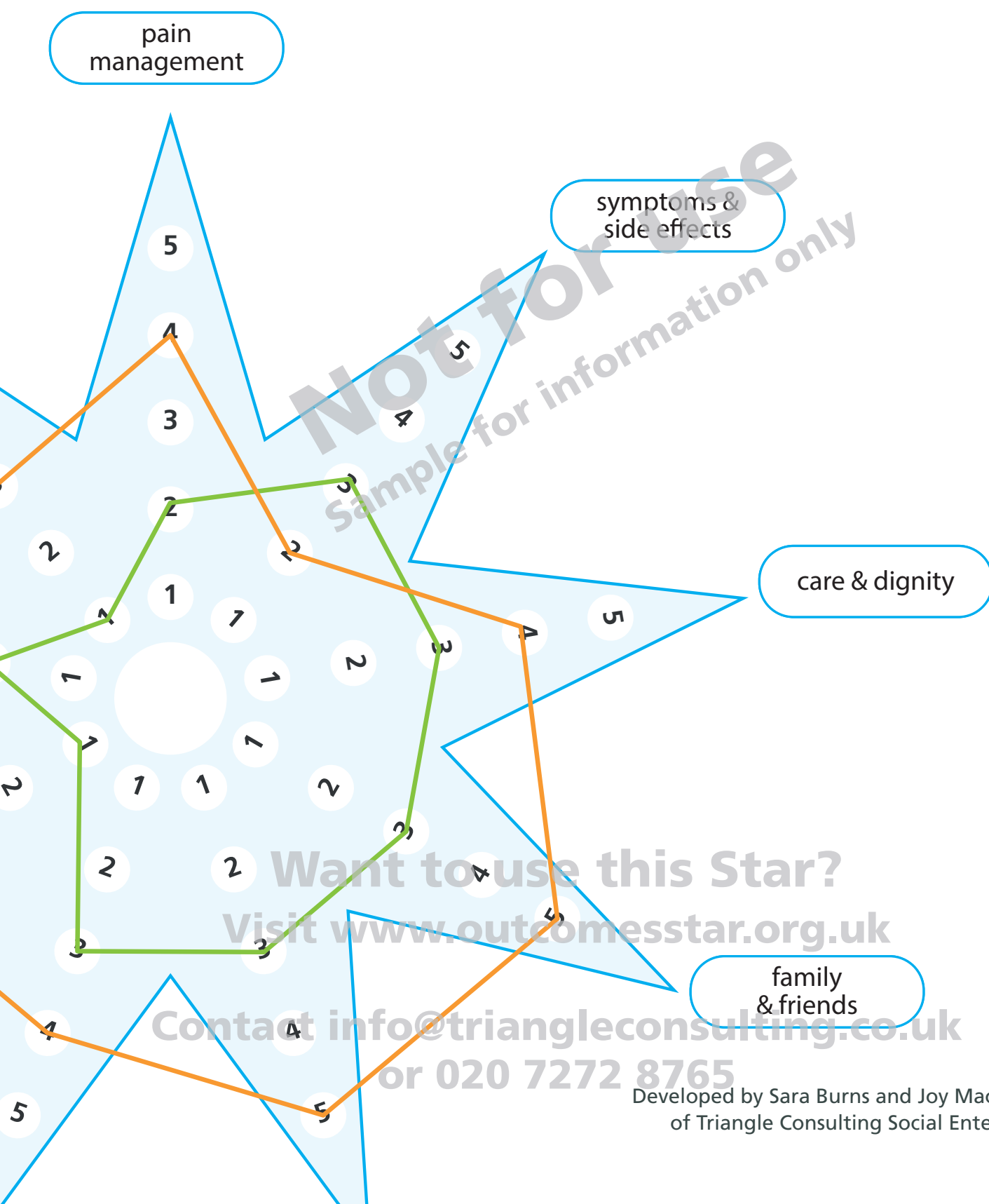




Preparation Star™

The Outcomes Star for living well right to the end



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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 and Guidance for Workers 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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Introduction

The Preparation Star is a visual tool to support conversations about what is important to people when they consider their final years or months. It may be most relevant for people following a diagnosis or for those who are elderly or have a health condition, but is also relevant to all of us and positive to reflect on at any point in our lives. It can be used to start and guide a conversation with professionals, support workers, family, friends or others – or for internal reflection.

It is a version of the Outcomes Star, a suite of tools for supporting and measuring change when working with people.

Star areas

The Preparation Star covers nine areas for discussion and there is a scale for each:

1. Pain management
2. Symptoms and side effects
3. Care and dignity
4. Family and friends
5. Doing what matters to you
6. Finances
7. Legal and practical aspects
8. Advance wishes
9. How you feel

You can choose which of these areas you would like to talk about first. Many people find that they want to talk about different areas at different times.

Each area is described on a scale.

The Journey of Change

Change does not happen in one go – it's a journey, and it can help to understand the steps along the way. All the Preparation Star scales are underpinned by a model of change that has five stages.

1. Not yet dealing with this
2. Finding out
3. Trying things out
4. Finding what works
5. As good as it can be

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A shared responsibility

Throughout the scales, making things as good as they can be will be down to a combination of you, your family, your medical team and anyone else involved in your care. Looking into options, trying things out and finding what works may be something that you do yourself or that others do on your behalf, depending on how well you are and the extent to which you want to make those decisions for yourself.

In the first three scales, making progress is largely the responsibility of those providing your medical and other care, in consultation with you and your family as far as possible. In the other six scales, it is more about you and those close to you, drawing on support as needed.

The Journey of Change

1 Not yet dealing with this

At the beginning of the journey you are experiencing difficulties or are worried about an aspect of your life but you or others are **not yet dealing with this**, so things are not improving. Sometimes, particularly in the areas covered in the first three scales of the Star, this is because you don't have the medical or other care or support you need at the moment. Other reasons might include feeling it's too early to address these issues, not wanting to burden others, thinking only you can sort it out or feeling too ill, in too much pain or too exhausted to give it any thought.

2 Finding out

At this stage you and/or others are **finding out** more about your options and what is possible, but haven't yet made decisions or started to make changes. You may be looking into things yourself or this may be mainly the responsibility of medical or support staff. You probably have help with urgent issues, especially in the first three areas, and may be talking to someone about the choices open to you.

3 Trying things out

At this stage you are **trying things out** and where there are major decisions to be made you are making those choices. However you have not found solutions that work well for you or you have not yet implemented big decisions, so you are not yet experiencing much benefit.

4 Finding what works

The next stage is **finding what works**. You and perhaps others have a sense of what is important to you at this time and are finding ways to make that happen. This may be finding ways to spend time with people, doing things you value, sorting out practicalities and/or managing any medical issues. If there were major decisions to make, such as about where you live, you have now made those choices and acted on them. However, there is more that could be done for things to be as good as possible.

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5 As good as it can be

The final point of the Journey of Change is **as good as it can be**. You and those close to you can be confident that you have done what you can for now. Your affairs are sufficiently in order so that you can live as well as possible right to the end without extra worries or difficulties. You have communicated your choices about things that matter to you to the people who need to know, or you trust them to make choices for you. You may feel a sense of calm, peace or comfort in your connections with others. If things change, then further adjustments may be needed and you may move to a different point in the journey, but for now things are **as good as they can be**.

These stages are colour-coded as well as numbered.

Not for use
Sample for information only

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1 Pain management

Effective pain relief, responding to your needs, addressing worry about future physical pain

5 As good as it can be

My pain is managed as well as it can be for now and I trust people to act according to my wishes

4 Finding what works

My pain is reasonably well managed, but this could be better

3 Trying things out

The medical staff and I are trying to find ways to manage my pain, but it's difficult

2 Finding out

I'm getting help and finding out what the options are for managing pain

1 Not yet dealing with this

I have a lot of pain or worry about future pain and don't have help with this

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1 Pain management (detail)

This scale is about managing physical pain to find a balance that feels right for you between effective pain relief and living your life as fully as possible. It includes medical staff doing what they can to manage any pain you are experiencing as well as possible, according to your wishes. It also includes people discussing with you how to manage future pain. If you don't have any pain or anxieties about pain, place yourself at 5.

5 As good as it can be

My pain is managed as well as it can be for now and I trust people to act according to my wishes

- Your pain is under control and managed well, in accordance with what you want, or the medical team has done all they can and you agree that it's as good as it can be
- You may be taking an active lead in managing your pain and medical staff are coordinating well. You have found the right balance for you between pain relief and being alert or able to do the things that are important to you
- You have discussed your wishes for pain management in the future with the medical team and/or people close to you and are confident that these will be carried out

4 Finding what works

My pain is reasonably well managed, but this could be better

- Medical staff are finding effective ways to help control your pain, and you may be starting to feel in control yourself. If you are using other methods to help manage pain, you are finding what works best for you
- You may be planning what to do if your pain becomes worse
- Things are improving in this area but there are still a few issues

3 Trying things out

The medical staff and I are trying to find ways to manage my pain, but it's difficult

- You and/or medical staff are trying out new ways to relieve your pain but you may experience new side effects such as constipation or nausea and don't have the right balance yet
- You may be experimenting with other methods to help you manage pain, such as relaxation techniques, exercise or mindfulness
- You may be trying to find a good balance between pain relief and being alert or able to do things that are important to you, but are not there yet
- You and medical staff are making efforts but have not yet found what works for you

2 Finding out

I'm getting help and finding out what the options are for managing pain

- As for 1, your pain is not yet being managed effectively or you are anxious about future pain, but medical staff are looking at your options
- If you have been given pain medication or treatment, it's not working well. You may be finding out more about what might help
- You may be discussing options for balancing pain relief with being alert or able to do the things that are important to you

1 Not yet dealing with this

I have a lot of pain or worry about future pain and don't have help with this

- You are experiencing strong pain but it's not being managed effectively and/or you are anxious about how bad it may get in the future
- You may be waiting for medical staff to respond. Perhaps it isn't easy to access pain relief where you are or you need people to coordinate better
- You are not yet getting the help you need. You may think you just have to put up with it, hope it will go away on its own, don't know what your options are to control it or don't take your pain medication, perhaps because of the side effects. You may not have discussed this with medical staff

2 Symptoms and side effects

Managing symptoms, effects of treatment, other medical needs, reviewing medical care

5 As good as it can be

My symptoms or side effects and medication are managed as well as they can be

4 Finding what works

My symptoms or side effects and medication are mostly well managed but need some adjustment

3 Trying things out

Medical staff and I are trying ways to manage my symptoms or side effects, but it's difficult

2 Finding out

I have symptoms or side effects that cause me distress, but I have help to find out about options

1 Not yet dealing with this

I have symptoms or side effects that cause me distress and don't have the help I need

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2 Symptoms and side effects (detail)

This scale is about managing any symptoms or difficulties such as breathlessness, confusion, memory loss, exhaustion, speech issues, shaking, mobility issues, incontinence, digestive issues, skin problems or sexual problems. It is also about medical staff reviewing your medication holistically and involving you in choices about treatment. You can use this scale to discuss balancing treatment, side effects and quality of life.

5 As good as it can be

My symptoms or side effects and medication are managed as well as they can be

- Any symptoms or other physical difficulties you experience are mostly under control or as good as they can be, or you have chosen to live with them as the best option for now
- Medical staff are coordinating well, have reviewed your medication to see what makes sense for you now, and have reduced unwanted side effects as far as possible
- You have discussed treatment choices with medical staff and others close to you, are confident that they will be carried out and know you will have support if things change

4 Finding what works

My symptoms or side effects and medication are mostly well managed but need some adjustment

- You are finding ways to address symptoms or other physical difficulties, or you accept how things are, but some things could be better
- Medical staff are doing their best to manage any side effects and may reduce or stop some medication to improve your quality of life. They are reviewing it as a whole to see what is appropriate for you now
- You have made any choices about treatments or interventions that would impact your quality of life, and may be putting them into practice
- Things are improving in this area but there are still a few issues

3 Trying things out

Medical staff and I are trying ways to manage my symptoms or side effects, but it's difficult

- You and/or medical staff are trying out ways to reduce any symptoms or other physical difficulties or manage them better but have not yet found what works best
- You may be talking with medical staff about your priorities and they may be trying to coordinate your care
- You may be trying to make choices based on what effect taking or not taking a particular treatment could have on your quality of life
- You and others are making efforts but have not yet found what works for you

2 Finding out

I have symptoms or side effects that cause me distress, but I have help to find out about options

- As for 1, but you and medical staff recognise the effect that symptoms, side effects or other physical difficulties are having on you and are trying to understand the situation and explore options

1 Not yet dealing with this

I have symptoms or side effects that cause me distress and don't have the help I need

- You may be distressed by symptoms such as breathlessness, confusion, memory loss, exhaustion, speech issues, shaking, mobility issues, incontinence, digestive issues, skin issues, fragile skin or sexual problems
- You may have side effects from treatment that reduce your quality of life, your medication may not be right for you now, or you may have difficulty swallowing it. Perhaps no one has reviewed your medication recently
- You are not yet getting the help you need. Perhaps you feel unable to seek help or don't have access to it. Perhaps medical staff are not coordinating well enough or are concentrating on one illness but not on other issues

3 Care and dignity

Being in the right surroundings, quality and responsiveness of care, comfort and dignity

5 As good as it can be

I have the right care and am comfortable where I am for now. I have made decisions about future care

4 Finding what works

I'm sorting out my care and any changes needed in my home, but there are still some issues

3 Trying things out

I'm trying to manage with different care or to make changes at home, but it's difficult

2 Finding out

I don't have the care I need or things are not right in my home, but I'm finding out about options

1 Not yet dealing with this

I don't have the care I need or things are not right in my home. I don't have help with this

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3 Care and dignity (detail)

Whether you are living in your own home, a care home, nursing home or elsewhere, this scale is about having care and surroundings that help you to feel comfortable and able to live your life as fully as possible. It includes having as much choice and control as possible and the things that help you be yourself and feel at home. It also covers feeling at ease with carers and being treated with dignity and kindness.

5 As good as it can be

I have the right care and am comfortable where I am for now. I have made decisions about future care

- You manage well and have any care or support you need so people aren't too worried about you. If your carer is a member of your family, they are well supported
- You are happy with your care, feel treated with dignity, warmth and kindness, and are able to live your life as fully as possible in your current circumstances
- You are comfortable enough in your surroundings and feel as much at ease as is possible
- You have made decisions about the kind of care you would like if your health or mobility worsens and feel confident that your choice will be respected

4 Finding what works

I'm sorting out my care and any changes needed in my home, but there are still some issues

- You mostly have the care you need to manage for now, such as help with bathing, eating or cleaning
- If you needed to move somewhere more suitable, you have everything in place. If you have moved recently, you are still settling into your new home
- You may be improving aspects of your surroundings so you feel more comfortable there
- Things are improving in this area but there are still a few issues

3 Trying things out

I'm trying to manage with different care or to make changes at home, but it's difficult

- You are trying out options to get some of the care you need to manage, such as help with bathing, eating or cleaning
- You may be planning where you live or your care for the longer term. This may include making decisions about moving, perhaps to sheltered accommodation, a nursing home or to live with a relative
- You may be getting equipment or other support you need to be safer or more independent
- You and others are making efforts but have not yet found what works for you

2 Finding out

I don't have the care I need or things are not right in my home, but I'm finding out about options

- As for 1, but you are finding out your care options and talking to someone about this. People are listening to you, but you and they haven't yet made choices or changes
- This may include you and/or a family member or worker exploring an immediate care package

1 Not yet dealing with this

I don't have the care I need or things are not right in my home. I don't have help with this

- You may need more or different care, perhaps with bathing, eating or cleaning, or you feel uncomfortable with your care or are not treated with dignity. Perhaps a member of your family is no longer able to manage caring for you or you don't want them to
- You may need or want to move or where you are staying isn't right for you now. If you are in your own home, you may feel anxious about being alone. If you are elsewhere, you may dislike it or feel you can't be yourself or do things for yourself there
- You are not yet getting the help you need. You may feel no one is listening, you don't know how to access better care, don't believe you need it, or think you have to put up with things as they are

4 Family and friends

Close relationships, support, communication with people you care about

5 As good as it can be

My connection with family or friends is as good as it can be at this point

4 Finding what works

I'm mostly able to connect with the people who matter to me, but there are still some issues

3 Trying things out

I'm trying to connect with people who matter to me, but it's difficult

2 Finding out

I want to feel connected to family or friends at this time and am exploring what I can do

1 Not yet dealing with this

I'm upset or worried about family or friends. I don't know what could help

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