When you have cancer, you don’t just worry about what will happen to your body, you worry about what will happen to your life. How to talk to those close to you. What to do about work. How you’ll cope with the extra costs.

At Macmillan, we know how a cancer diagnosis can affect everything. So when you need someone to turn to, we’re here, because no one should face cancer alone. We can help you find answers to questions about your treatment and its effects. We can advise on work and benefits, and we’re always here for emotional support when things get tough.

Right from the moment you’re diagnosed, through your treatment and beyond, we’re a constant source of support to help you feel more in control of your life.

We are millions of supporters, professionals, volunteers, campaigners and people affected by cancer. Together we make sure there’s always someone here for you, to give you the support, energy and inspiration you need to help you feel more like you. We are all Macmillan.

For support, information or if you just want to chat, call us free on 0808 808 00 00 (Monday to Friday, 9am–8pm) or visit macmillan.org.uk
The Macmillan Values Based Standard® was developed through an 18-month engagement process with more than 300 patients and their carers, along with healthcare professionals. The idea was to develop a standard for cancer care services based upon human rights principles. It builds on the views and aspirations of patients, carers and professionals to provide a framework for improving patients’ and professionals’ experience of healthcare. It identifies specific behaviours – practical things that you can do on a day-to-day basis to ensure that people’s rights, including dignity and respect, are protected. It focuses on the ‘moments that matter’ to people and their carers. It builds increased trust and improved relationships between professionals, patients and carers, leading to more opportunities to identify problems earlier for higher patient satisfaction.

*Please note that in referring to professionals we are including all roles within your healthcare organisation that have a relationship or come into contact with patients and carers.

‘The Macmillan Values Based Standard works. It isn’t just about cancer, it’s about people, it’s about human connection, it’s about what makes a good experience for everybody involved.’
CEO, John Taylor Hospice
The Macmillan Values Based Standard focuses on behaviours that will improve patient experience. The behaviours represent the areas that matter most to people affected by cancer and were also developed to resonate with what matters to you in your role as a health professional.

In this way, the Macmillan Values Based Standard is more accurately described as person-centred as it is about professionals and patients. Evidence is beginning to suggest that patient-centred care is associated with good health outcomes and cost-effectiveness, with lower costs and shorter inpatient stays.

Implementing the Macmillan Values Based Standard is not a one-off project: it is a way of working. It’s about how you and your organisation can adapt it to the workplace. Each implementation is unique to the site or ward, and rarely mirrors another. However, the approach and methodology is always the same, and recognisably part of the framework of the Macmillan Values Based Standard. It is how this framework is implemented that engages professionals and includes patients. Although the Macmillan Values Based Standard was originally developed for cancer care, organisations across health and social care are using it to improve the experience of all patients.

This booklet sets out what these behaviours are and the framework you can use them in to implement change. It also shows how you begin to practically apply this to make changes; and what tools and support are available to you as you begin to implement the Macmillan Values Based Standard.

1. How can it help improve the experience of patients and professionals?

The Macmillan Values Based Standard is structured around eight behaviours. These are designed to effect positive change in professionals’ and patients’ relationships, drive up performance – especially in patient experience, satisfaction and outcomes – and protect care rights. The eight behaviours and what these mean to patients are described as:

**Naming**
You’re the expert on you and the information you give professionals will help them understand you. ‘I am the expert on me.’

**Acknowledge me if I’m in urgent need**
You can expect professionals to understand your needs and say when these will be met. However, there may be times when others are in more urgent need of care. ‘I’d like to not be ignored.’

**Private communication**
You’re entitled to privacy – you decide if information can be shared and who with. ‘My business is my business.’

**Control over personal space and environment**
Expect to be cared for in a clean and comfortable setting and say what you need for this to happen. ‘I’d like to feel comfortable.’

**Communicating with more sensitivity**
Expect to be communicated with in a sensitive way, be offered support and share any concerns about what you’re told. ‘I’m more than my condition.’

**Managing on my own**
You should be supported to manage your own care but also know where to go if you’re worried or need support. ‘I don’t want to feel alone.’

**Clinical treatment and decision making**
Be involved in decisions. You should be informed of the treatment options and why recommendations have been made. This includes how the treatment will make you feel and any longer-term effects. ‘I’d like to understand what will happen to me.’

**Getting care right**
Your feedback is always welcome and your concerns are acted on, as part of a process to improve your experience of care. ‘My concerns can be acted upon.’

For more detailed descriptions of each behaviour, vocational examples of their use and their positive outcomes, please refer to section 6 of this booklet.

The Macmillan Values Based Standard provides a credible method for understanding and measuring patient experience. And it does this by focusing on standards of behaviour chosen for their potential to improve professionals and patient relationships and the care experience. It makes an explicit link between delivering care outcomes and the patient’s entitlement to be treated with dignity, respect and equity by those who deliver their care.

‘It doesn’t feel like another top-down initiative – it feels like a conversation professionals can become part of and influence.’

CEO, John Taylor Hospice
3. The framework

The model below sets out the eight behaviours that make up the standard but also the foundations that need to be in place to really make a difference. This is not a project – it is an organisational focus on continuous improvement with professionals and patients working together to design and implement improvement.

Rather than performance benchmarks ‘imposed’ from above, the framework of the Macmillan Values Based Standard emphasises co-productive behaviours between professionals and patients. Applying this to your organisation can be a process of change to improve the experiences of those who receive and give care.

Implementing the Macmillan Values Based Standard Framework

**FOUNDATIONS**

<table>
<thead>
<tr>
<th>Care is person-centred</th>
<th>There is a culture of enabling leadership</th>
<th>Robust facilitation is available</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients are equal partners in the planning, development and assessment of their care, making sure it is most appropriate for their needs</td>
<td>People are given permission to act as leaders no matter where they sit in the organisation. This kind of distributed leadership supports professionals to make improvements</td>
<td>This will support multiple stakeholders to work together when implementing the framework</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Co-design principles are being applied</th>
<th>‘Bottom up’ and permission based approaches are in place</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professionals and patients work together to design improvements</td>
<td>Front-line professionals are best placed to lead the improvement of the patient’s experience of care and all professionals are empowered to respond to patients’ needs</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Measurement and feedback processes are in place</th>
<th>Professionals are practising reflective learning</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is important to use a number of ‘measures’ to help see whether patients’ and professionals’ experiences are improving</td>
<td>Professionals are encouraged to look back at their own practice and consider what and how they have achieved, and also what they might also change</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>There is an evidence base demonstrating need and impact</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Evidence is used to demonstrate why relational care is needed, and to track the impact of improvements made</td>
<td></td>
</tr>
</tbody>
</table>

**BEHAVIOURS**

<table>
<thead>
<tr>
<th>Naming</th>
<th>Private communication</th>
<th>Communicating with more sensitivity</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘I am the expert on me’</td>
<td>‘My business is my business’</td>
<td>‘I’m more than my condition’</td>
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</table>

<table>
<thead>
<tr>
<th>Clinical treatment and decision making</th>
<th>Acknowledge me if I’m in urgent need of support</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘I’d like to understand what will happen to me’</td>
<td>‘I’d like not to be ignored’</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Control over personal space and environment</th>
<th>Managing on my own</th>
<th>Getting care right</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘I’d like to feel comfortable’</td>
<td>‘I don’t want to feel alone in this’</td>
<td>‘My concerns can be acted upon’</td>
</tr>
</tbody>
</table>

**OUTCOMES**

Improving patients’ and professionals’ experiences

Culture change
4. How to apply the framework to improve patients’ and professionals’ experiences

When implementing the Macmillan Values Based Standard in your organisation, we encourage a three-phase approach. In summary this concentrates on:

**Discover**
- **What is really going on here?**
  - Use survey data, annual and real time
  - Work with professionals – identify system failures
  - Interview patients, run focus groups
  - Observation
  - Identify front line improvement teams/leads

**Innovate**
- **What interventions might help?**
  - Professionals and patients co-design interventions
  - Agree measurement systems
  - Small tests of change, evaluate and refine
  - Diffused leadership and permissions to respond to individual need
  - Workplace reflection, learning and support

**Improve**
- **Measure, sustain and spread improvement**
  - Develop measurement systems that ensure on-going improvement
  - Continually involve patients and professionals in understanding ‘how we are doing’
  - Embed workplace reflection
  - Develop a plan for spreading good practice, including corporate processes such as recruitment, induction and appraisal
  - Feedback results – Ward to Board

This is all about building up a really good picture of the current experience of patients and professionals. This will generate the evidence you need to decide on improvements.

- The first step is to consider what data (qualitative and quantitative) you may already have – what is it telling you?
- Set up a steering group or project group to help support the work
- Run a staff workshop in the area you want to start in
- Interview professionals and/or run an anonymous survey
- Interview patients and/or run a focus group – talk to some relatives
- Use observation as a tool to understand more
- Establish a base line that you can re-visit in future

This stage is about involving a wider group of people and gaining agreement about what interventions you are going to focus on.

- Run a way forward event where you present your evidence from the discovery phase
- At the event agree the broad areas you want to concentrate on – do not decide at this stage on specific interventions
- Decide who will lead the work areas – professionals? Former patients? Get the relevant permissions
- Decide how you will involve patients in helping shape and implement the interventions
- Use the model for improvement and small tests of change
- Set up systems for review and personal reflection

This stage is all about sustaining the gains you have made and implementing your strategy for spread across the organisation.

- Consider who is best placed to ensure the work continues
- How will this be measured and where will it report to?
- Consider ways in which professionals can remain involved
- How are decisions being made about where to implement the values next
- Ensure your corporate practices are mirroring the values
- What role is leadership playing?
- Celebrate success and make feedback public

As with all change programmes, commitment from senior leaders is vital. This will ensure that you’re encouraged to make positive changes and recognised for this work. Senior support is also necessary to ensure the spread of the work throughout the organisation. This should happen through linking this work to other change programmes, as well as other corporate practices such as recruitment and appraisal.

‘It has improved our patient experience because patients are being asked what they want to be asked and what is important to them. As a ward manager it has given me an idea of where the ward has to improve.’

Senior Nurse, Imperial College NHS Trust
5. Tools and support

Macmillan Cancer Support is here to guide and support you through your implementation process with a number of methods.

1. Expert guidance

Macmillan Cancer Support has been helping sites implement the Macmillan Values Based Standard since 2012. We’re here to provide guidance and support about how to get started, how to get buy-in, and how to overcome obstacles that arise. Implementation will be a programme for you and your site but we don’t expect you to go it alone. We will ensure that you get all the support you need as you undergo the process.

2. Collaborative events

We run collaborative events for all sites implementing the Macmillan Values Based Standard. The events bring new and existing organisations together to share best practice and learning in implementing the approach across organisations and regions. It is mandatory that representatives from organisations implementing the Macmillan Values Based Standard attend. This is a great opportunity for people leading the work at the frontline to meet others like themselves at various stages of implementation. For more information please contact your Macmillan Development Manager, or email: Patientexperience@macmillan.org.uk

3. Learnzone.org.uk

We also have an extensive range of online resources for you to look through and use. On Learnzone, you’ll find:
- videos about the experience of implementing the Macmillan Values Based Standard
- tips for engaging professionals
- guides to getting started
- case studies to support implementation
- useful tools and resources to support your implementation
- Your cancer care leaflet, an information resource for patients and carers
- presentations and visual resources

6. Detailed descriptions of the behaviours

NAMING:
'I AM THE EXPERT ON ME.'

Leadership behaviour

Leaders create a personable and approachable environment across the staff structure. They want ideas and innovation to emerge from the frontline, reinforcing the importance of all roles in the organisation.

Leaders ‘role model’ behaviours that emphasise the importance of relationship-building because they want to encourage professionals to develop better relationships with all patients.

Vocational ‘nudge’ examples

‘I want to know who patients really are.’

‘I recognise the need to understand what is important to patients and that this information can be of assistance to me in understanding how to care for patients.’

Professionals ensure that patients are asked how they want to be addressed in every new professional/patient interaction and act on this information.

Professionals ensure that this initial introduction supports the gathering of essential information such as language, support requirements, disability issues, and religious and dietary needs.

Patients help professionals understand what is factual and what is presumed and take greater responsibility for the information they provide.

Professionals are open to correcting incorrect patient information.

Outcome: Patients can disclose information which will help professionals to understand them and act on their needs.

Naming

Private communication
Communicating with more sensitivity
Clinical treatment and decision making
Acknowledge me if I’m in urgent need of support
Control over personal space and environment
Managing on my own
Getting care right
PRIVATE COMMUNICATION:
'MY BUSINESS IS MY BUSINESS.’

Leadership behaviour
Vocational ‘nudge’ examples
Behavioural standard for improving cancer care

Plans are drawn up to address confidentially issues, especially where private space is not easily available.
Professionals are supported in their endeavours to provide private consultation to patients.
Leaders discourage inappropriate communication between professionals or between professionals and patients.

‘I want to give you the space you need.’
‘I recognise that however many times I have conveyed this type of information, this is your news and your first time hearing it.’
Professionals ensure that consultations with patients are made private and that patients are informed when this isn’t possible.
Patients may have to acknowledge that complete privacy is not always possible.
Professionals ensure that patients are involved in decisions about the onward communication of information about them and their condition.
Patients take greater responsibility for determining disclosure.

Outcome: The patient has space to listen and hear information and can be secure in their reaction to the information received. The patient decides if they want information to be shared and who with.

COMMUNICATING WITH MORE SENSITIVITY:
‘I’M MORE THAN MY CONDITION.’

Leadership behaviour
Vocational ‘nudge’ examples
Behavioural standard for improving cancer care

Leaders communicate regularly with professionals and consider how they use communication to motivate and encourage professionals to do the best job.
Leaders put plans in place that support professionals more holistically in carrying out their roles.
Professionals ensure that they explain the seriousness of the intended communication, and observe and respond appropriately to the emotional, physical and psychological impact of the information.
Patients are enabled to share their concerns.
Professionals ensure that patients are offered support and involved in determining their needs.

‘I want to understand the impact of my communication so that I can alter my approach to respond to your needs.’
‘I will respond patiently to your questions and concerns.’
‘I will prompt you with some possible questions, to give you time to reflect.’

Professionals ensure that they

Outcome: Patients are empowered to share any concerns about what they’ve been told. Patients receive better support based on their reaction to information.
CLINICAL TREATMENT AND DECISION MAKING: "I'D LIKE TO UNDERSTAND WHAT WILL HAPPEN TO ME."

Leadership behaviour
Leaders listen to professionals and involve them appropriately in negotiating decisions that impact on their roles.
Leaders appraise and understand patient data, noticing in particular who’s likely to receive the best and worst outcomes within their care.
Leaders use a range of data sources, especially those that relate to feedback from patients and professionals.
Leaders encourage professionals to represent patient concerns, especially where this conflicts with achieving the Macmillan Values Based Standard®.

Vocational ‘nudge’ examples
'I want you to know – even when telling you is challenging or uncomfortable for me – I will be supportive in your need to understand the options.'
'I have knowledge and you have knowledge: we will explore the options and negotiate the decisions.'
'It’s important that I put aside my personal values and “health beliefs” when they collide or conflict with the wishes of a patient.'

Behavioural standard for improving cancer care
Professionals ensure that the next stages in clinical processes are explained. These will include timescales and the type of support needed to help patients through the treatment process. In addition, they’ll also look at how the treatment will make people feel and any consequences of the treatment – short, medium or longer term.
Patients contribute by asking questions and sharing concerns.
Professionals ensure that patients’ practical support requirements are discussed.
Professionals ensure that patients are involved in negotiating their treatment.

Outcome: Patients understand which options have been considered and why recommendations for a particular course of treatment have been made. They know how to prepare for the treatment and have a better understanding of the associated short, medium and longer-term treatment consequences. Patients feel more engaged in their treatment plan.

ACKNOWLEDGE ME IF I'M IN URGENT NEED OF SUPPORT: 'I'D LIKE NOT TO BE IGNORED.'

Leadership behaviour
Leaders acknowledge where there may be pressure points in the system, and assist professionals in prioritising the delivery of their care role in line with the standard.
Leaders take notice of data and use it to create opportunities for service improvement.
Leaders encourage professionals to innovate in their quest for solutions to provide patient satisfaction.
Leaders are prepared to recognise the need for system change, especially when indicated by professionals at the frontline.

Vocational ‘nudge’ examples
‘You can trust me – I’ll be honest with you and tell you when you have to be patient.’
‘It will take some thinking about the practicalities, but I won’t mislead patients or use routine statements to pacify patients in need.’
‘I’ll do my very best not to forget you, and update you on when I’m able to attend to your needs.’

Behavioural standard for improving cancer care
Professionals ensure that they acknowledge patient need by letting patients know that they have recognised that they are in need of support.
Patients may sometimes have to recognise that others have more urgent needs.
Professionals ensure that they indicate to patients when their needs may be met.

Outcome: Patients’ care needs are acknowledged, but they also understand that others may be in more urgent need of care, and that they may have to wait for support from professionals.

Naming
Private communication
Communicating with more sensitivity
Clinical treatment and decision making
Acknowledging me if I’m in urgent need of support
Control over personal space and environment
Managing on my own
Getting care right
**Leadership behaviour + Vocational ‘nudge’ examples + Behavioural standard for improving cancer care**

**Leadership behaviour**

Leaders receive data on staff motivation and wellbeing, by service, team and consultant. They actively monitor this data for trends, especially in relation to issues of grade, function or protected characteristics.

Leaders appraise information on patient welfare and hygiene issues recognising where the service has been able to act on patient concerns. And they offer explanations if patient concerns have not been met.

Leaders provide professionals with flexibility, opportunities to influence policies and the use of resources to encourage innovation and improve patient experience.

**Vocational ‘nudge’ examples**

‘If you’re happy then I’m happy – I’ll make it my business to check up on your immediate environment.’

‘I won’t mind or get defensive if you point out where there are problems – I’ll try not to take it personally.’

‘I will be the problem-solver whenever a patient’s comfort is compromised, and I’ll let the patient know if I can’t improve the situation.’

‘I’ll be an agent for change – noting when the system is at odds with legitimate needs.’

**Behavioural standard for improving cancer care**

Professionals ensure that they ask patients about their comfort and respond to these needs where possible.

Patients inform professionals if they are uncomfortable and explain why.

Professionals explain if particular needs cannot be met. If appropriate, highlight these requirements to others in the system who may be able to resource this in the future.

Professionals ensure that the patient environment is clean, and attend to their own hygiene needs before supporting patients.

**Outcome:** Patients are able to express their comfort needs, have these needs met, and be cared for in a clean environment.

**Leadership behaviour + Vocational ‘nudge’ examples + Behavioural standard for improving cancer care**

**Leadership behaviour**

Leaders actively support vocational excellence and recognise and encourage professionals in this endeavour.

Leaders enable professionals to have valuable reflection time, which in turn supports the implementation of their role.

Leaders reward professionals who have acted on patients’ interests.

Leaders develop strong partnerships with other support services to ensure patient needs are met.

**Vocational ‘nudge’ examples**

‘I will support you in making the transition from ward care to home care.’

‘I want to know what’s best for you – the who, where, and how in your healthcare journey.’

‘I want to do what’s best for you and will liaise with other professionals to ensure that your support needs can be met.’

**Behavioural standard for improving cancer care**

Professionals ensure that they have understood how patients wish to receive information on their onward care.

Patients disclose any anxieties they may have regarding their ability to self-care.

Professionals ensure that future care, including the managing of planned and unplanned events are discussed.

Professionals ensure that lifestyle changes are discussed and that patients are appropriately supported and signposted to further help.

Professionals assess the impact of information on patients and ensure that they understand what to do next and where to go to for support.

**Outcome:** Patients are enabled to manage their own care and recognise the ‘normal’ tolerances of their condition. Patients feel better able to control and manage their condition and to maintain their independence, while also understanding when and who to refer to should they be in need of support.
Leadership behaviour Vocational ‘nudge’ examples Behavioural standard for improving cancer care

Leaders promote and implement ‘real time’ feedback across their services, and encourage criticism as part of the improvement process. Leaders recognise that middle managers and professionals can be ‘squeezed’ within the change process. Therefore, they actively manage decision-making at appropriate levels of the organisation. Leaders ‘role model’ the acceptance of criticism and ‘walk the floor’ to understand more about patients’ and professionals’ experiences. Leaders take notice of patterns of care – who is most likely to make complaints, what they are most likely to complain about, and use this information to make positive change.

‘I want to get it right for you and will ask you what can be done better.’
‘I won’t take it personally, and will try to get it right for you when you are in my care.’
‘I am rewarded by your satisfaction with our care.’
‘I will raise concerns about other professionals or systems which I think have worked against your care.’

Professionals actively request feedback from patients on the quality of patient care. Patients cooperate by providing real-time feedback. Professionals act upon feedback to ensure that adequate support can be offered in ‘real time’. Professionals ensure that they respond positively to patient feedback, especially if it is negative.

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References:
2. The Human Rights Act 1998

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