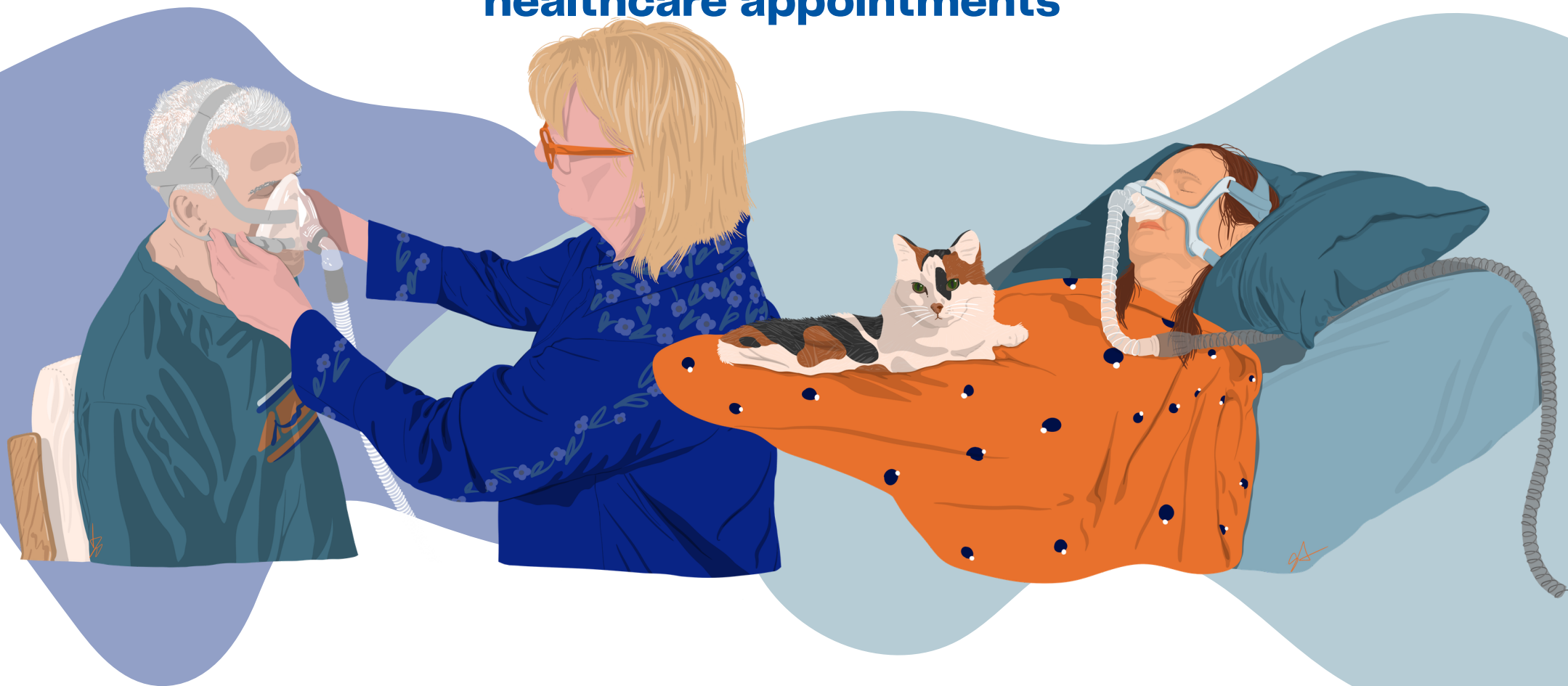


NON-INVASIVE VENTILATION (NIV) FOR PEOPLE LIVING WITH MND

**A question guide for making the most out of your
healthcare appointments**



TALKING WITH YOUR HEALTHCARE PROFESSIONAL ABOUT NIV

About this checklist

About this checklist

- This **question guide** is designed to help you and your family to talk with your healthcare team about **non-invasive ventilation (NIV)**.
- You can choose the questions that matter most to you and use them to help make decisions about your care.
- We recommend reading our useful one page **NIV information sheet** and watching our **NIV video series** on the [MND Australia website](#) prior to discussion with your healthcare professional.
- Use the space provided on each page to write down key points from your conversation. If you would like to record the conversation on your phone, always ask your healthcare professional for permission first.

When to use this checklist

- ☒ When you want to proactively learn more about future treatment options.
- ☒ During regular check-ups with your neurologist, respiratory doctor, palliative care doctor, or another member of your health team.
- ☒ If your healthcare team mention NIV as a potential treatment option.
- ☒ When you start experiencing breathing difficulties or tiredness.

You may have been diagnosed recently or a long time ago.
It is never too early or too late to talk your healthcare team about NIV.

Beginning the conversation

What is NIV, what are the benefits and risks?

When is the right time to start NIV?

How will NIV affect my daily life?

What happens if I choose NIV?

What happens if my doctor or I say 'No' to NIV?

Stopping NIV

BEGINNING THE CONVERSATION

About this checklist

Beginning the conversation

What is NIV, what are the benefits and risks?

When is the right time to start NIV?

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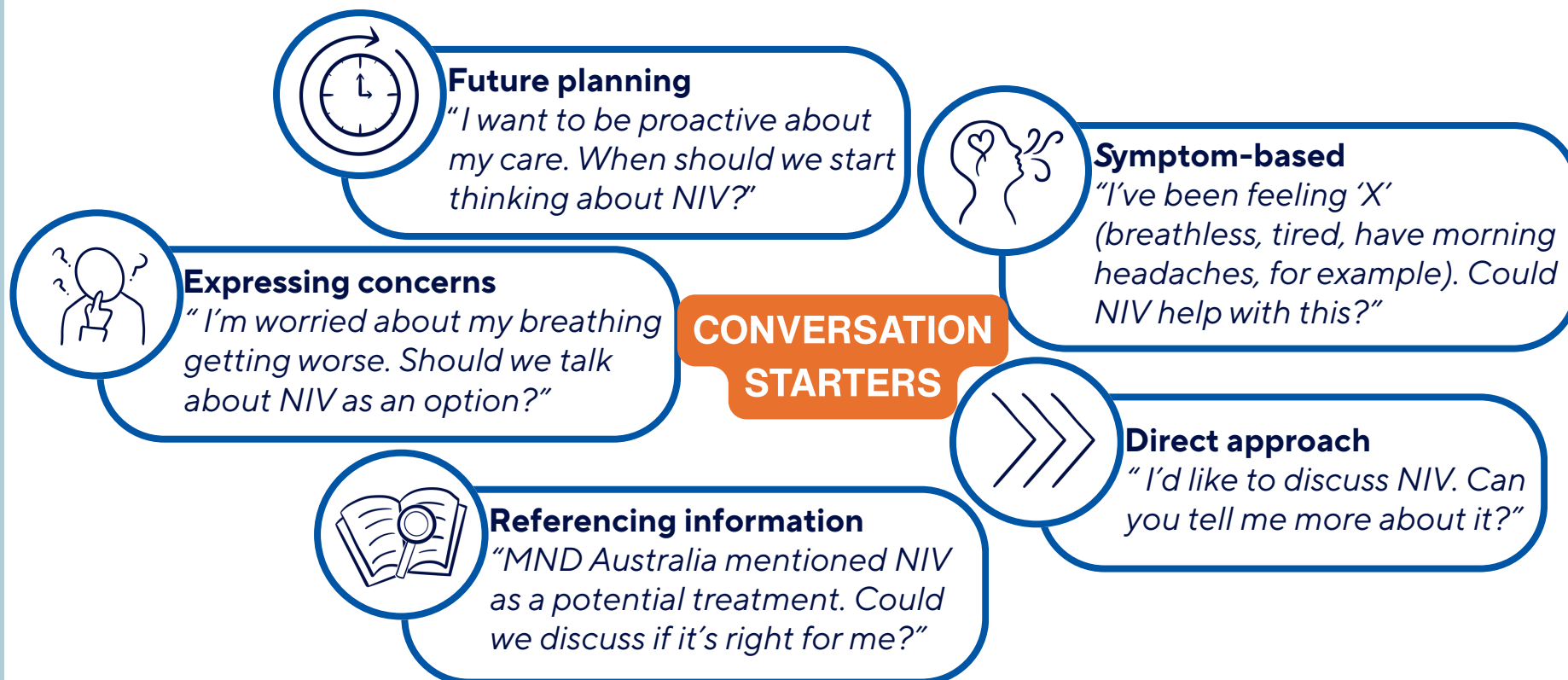
What happens if I choose NIV?

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Stopping NIV

How do I begin the conversation with my healthcare professional?

- Be open and honest about your concerns and symptoms.
- If you don't understand something, ask for clarification. You might say, "Could you explain that in simpler terms?" or "Could you give me an example of what that means?"
- Consider bringing a family member or friend to help you remember information and ask other questions.
- Remember, there are no "silly" questions when it comes to your health.
- Don't know how to start the conversation? Check out a few examples below.



WHO IS INVOLVED IN NIV CARE?

About this checklist

Beginning the conversation

What is NIV, what are the benefits and risks?

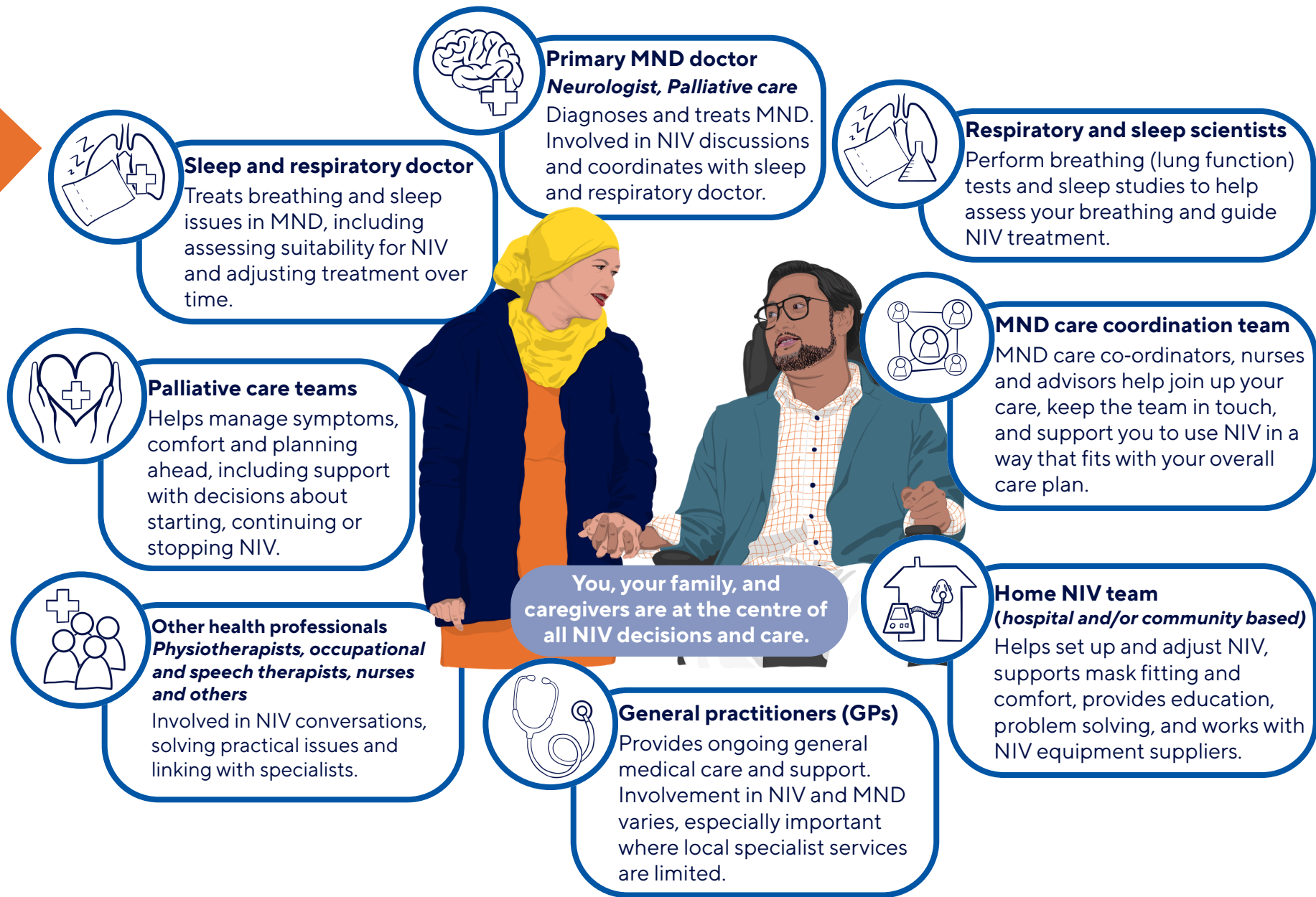
When is the right time to start NIV?

How will NIV affect my daily life?

What happens if I choose NIV?

What happens if my doctor or I say 'No' to NIV?

Stopping NIV



Not everyone will see all of these people. Your NIV team will look different depending on where you live, local services, and how your care is funded.

WHAT IS NIV AND WHAT ARE THE POTENTIAL BENEFITS AND RISKS?

About this checklist

Beginning the
conversation

What is NIV, what are
the benefits and risks?

When is the right
time to start NIV?

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my daily life?

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I choose NIV?

What happens if my
doctor or I say 'No' to NIV?

Stopping NIV

Understanding NIV

- ☐ What is NIV?
- ☐ How does NIV work?
- ☐ What does NIV equipment look like?
- ☐ How is NIV different from CPAP?

Potential benefits and risk of NIV

- ☐ Will NIV help me live longer?
- ☐ How might NIV improve my symptoms and overall wellbeing?
- ☐ Are there any potential side effects or complications I should be aware of?
- ☐ How does NIV compare to other treatment options for respiratory issues in MND?



WHEN IS THE RIGHT TIME TO START NIV?

About this checklist

Beginning the conversation

What is NIV, what are the benefits and risks?

When is the right time to start NIV?

How will NIV affect my daily life?

What happens if I choose NIV?

What happens if my doctor or I say 'No' to NIV?

Stopping NIV

The right time to start NIV

- ☐ At what point in my MND journey should I consider starting NIV?
- ☐ What symptoms or test results suggest that I should start NIV?
- ☐ Are there any risks/benefits associated with starting NIV too early or too late?



HOW WILL NIV AFFECT MY DAILY LIFE?

About this checklist

Beginning the conversation

What is NIV, what are the benefits and risks?

When is the right time to start NIV?

How will NIV affect my daily life?

What happens if I choose NIV?

What happens if my doctor or I say 'No' to NIV?

Stopping NIV

Living with NIV

- ☐ Can you tell me what life might be like on NIV?
- ☐ What might the mask feel like?
- ☐ Will I be able to use NIV and still carry out my normal activities?
- ☐ How might NIV impact my mobility, ability to communicate or travel?
- ☐ How might NIV use impact my family or caregivers?

Changes over time with NIV

- ☐ How might my NIV use change over time?
- ☐ At what point might NIV no longer help me, and what are the next steps?
- ☐ How will my healthcare team monitor and adjust my NIV treatment over time?

WHAT HAPPENS IF I CHOOSE NIV?

About this checklist

Beginning the conversation

What is NIV, what are the benefits and risks?

When is the right time to start NIV?

How will NIV affect my daily life?

What happens if I choose NIV?

What happens if my doctor or I say 'No' to NIV?

Stopping NIV

Choosing NIV

- ☐ What happens if I choose NIV?
- ☐ What does the process of starting NIV involve?
- ☐ How long do I need to wait to start NIV?
- ☐ How much will NIV cost me?
- ☐ Are there support groups or resources for MND patients using NIV?
- ☐ What training will my caregivers and I receive?
- ☐ Will it change my normal sleep positioning or routine, or make it difficult to fall or stay asleep?
- ☐ How often will I need follow-up appointments?
- ☐ Who should I contact if I have problems or questions about my NIV?

A large, empty, light blue rounded rectangle with a blue and orange pen icon at the top right corner, intended for notes.

WHAT HAPPENS IF I SAY NO TO NIV?

About this checklist

Beginning the conversation

What is NIV, what are the benefits and risks?

When is the right time to start NIV?

How will NIV affect my daily life?

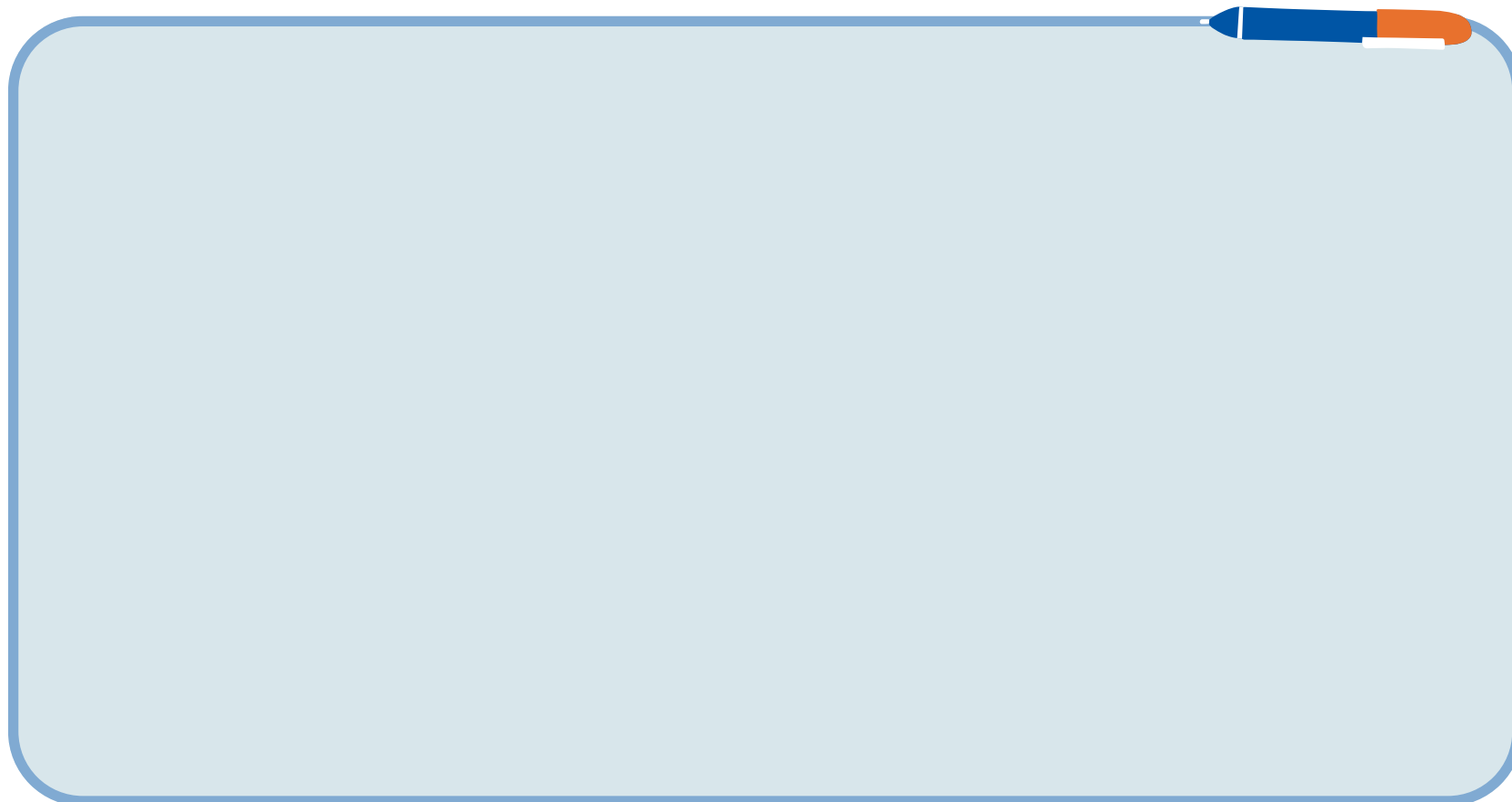
What happens if I choose NIV?

What happens if my doctor or I say 'No' to NIV?

Stopping NIV

Choosing not to use NIV

- ☐ What happens if I decide not to use NIV?
- ☐ What are the potential consequences of not starting NIV?
- ☐ What alternative treatments or management strategies are available?
- ☐ Will saying no to NIV affect my other treatments and care?
- ☐ Can I change my mind later if I decide I want to try NIV?
- ☐ How often should we revisit the discussion about NIV?
- ☐ What signs or symptoms should I watch for that might indicate I need to reconsider NIV?



WHAT HAPPENS IF MY DOCTOR SAYS NO TO NIV?

About this checklist

Beginning the conversation

What is NIV, what are the benefits and risks?

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What happens if I choose NIV?

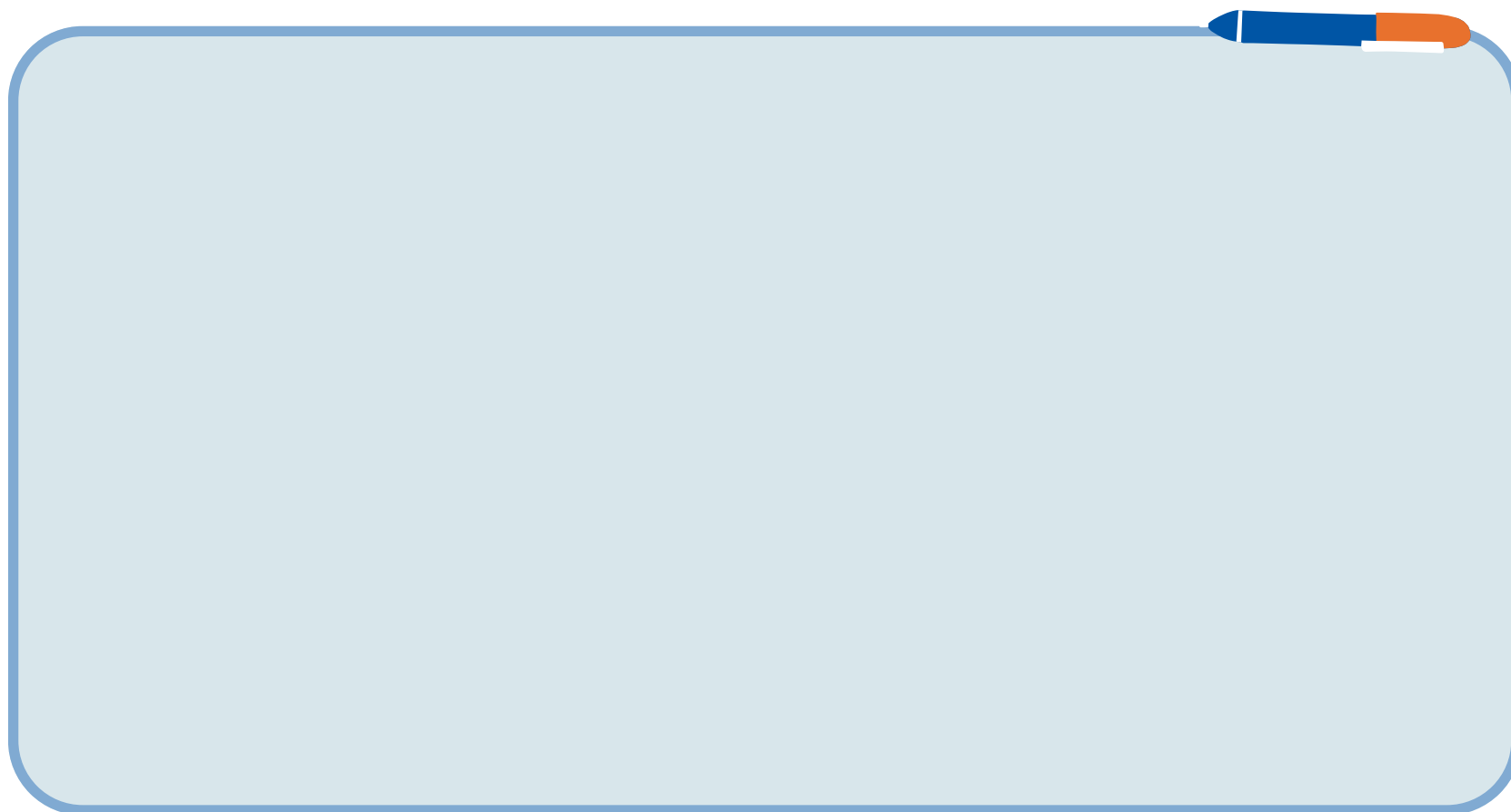
What happens if my doctor or I say 'No' to NIV?

Stopping NIV

What are my options if my doctor does not recommend NIV for me?

Occasionally, a person may be interested in starting NIV, but their doctor may recommend waiting or feel it is not the right option. If this happens to you and you want to better understand this decision or discuss your wishes, these questions may be helpful.

- ☐ Can you help me understand your reasoning for not recommending NIV?
- ☐ What criteria or conditions would need to be met for NIV to become an option?
- ☐ Would it make sense to discuss this with another healthcare professional for their opinion?



WHAT DO I NEED TO KNOW ABOUT STOPPING NIV?

About this checklist

Beginning the conversation

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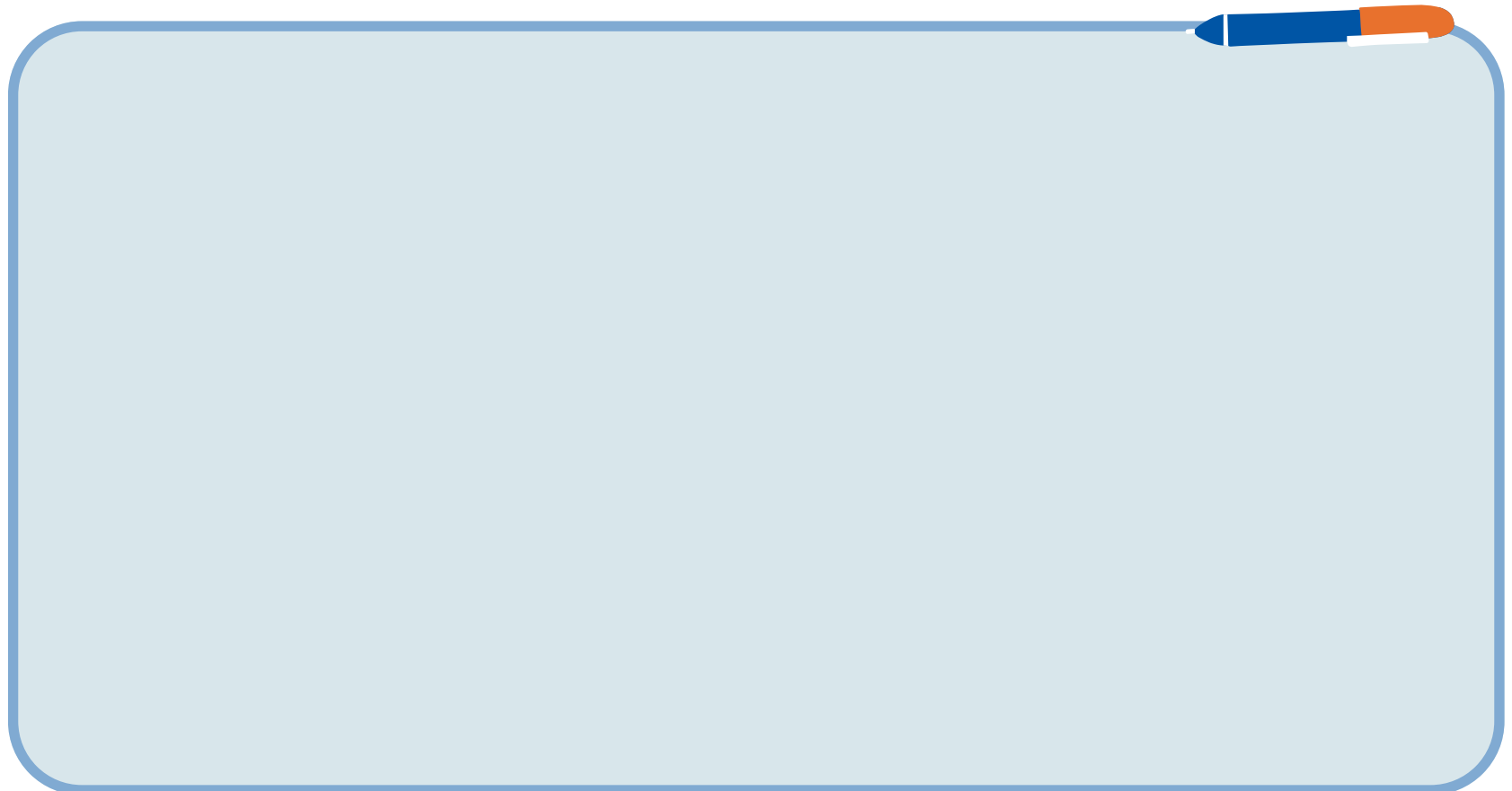
What happens if I choose NIV?

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Stopping NIV

Questions about stopping NIV

- ☐ Can NIV be stopped at a later stage if I don't want it anymore? How would that be managed?
- ☐ What do I need to know about stopping NIV?
- ☐ What symptoms might I experience if I stop using NIV?
- ☐ How will my care plan change if I stop NIV?
- ☐ What support is available to me and my family if I decide to stop NIV?
- ☐ How can I document my wishes about NIV in my advance care plan?



ADDITIONAL RESOURCES

Where can I find out more information on NIV?

MND Australia - Breathing and MND:

www.mndaustralia.org.au/breathing

Australian educational video series regarding NIV in MND:

www.vimeo.com/showcase/NIV

MND Decision Tool - Assisted Ventilation:

www.mnddecisiontools.com/public/3/decision_tool

UK educational website about breathing support in MND:

www.mybreathing.mymnd.org.uk/using-mybreathing/



WE NEED YOUR FEEDBACK!

To help us better support the MND community, we would greatly appreciate your feedback on this resource. **Scan the QR code or click the link below to complete a brief survey.**

[Click here](#)



ABOUT THIS RESOURCE

Acknowledgements

This research was generously supported by FightMND and MND Australia. This work was led by researchers at the Institute for Breathing and Sleep in collaboration with the NIV in MND Stakeholder Advisory Group and participants of the co-design project from the Australian MND community.



In collaboration with the research team, the design of this resource, along with illustrations, was created by Georgia Pope, of Vital Designs, Melbourne.

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The NIV in MND Question Prompt List is designed to support people living with MND, and those who care for them, to use during discussions with their healthcare team about NIV. It provides general information only and does not replace advice, diagnosis or treatment from a qualified healthcare professional. References to tests or treatments do not imply endorsement by the Institute for Breathing and Sleep. Decisions about care should be made in partnership with your healthcare team, taking into account your individual circumstances. Do not delay or change medical care based on information in this resource.