

Supporting my patient's wellbeing and adherence to neovascular age-related macular degeneration (nAMD) treatment through comprehensive communication

As part of the nAMD Barometer programme, designed to address non-adherence and non-persistence to treatment in patients with nAMD, a discussion guide has been developed to support clinicians in identifying certain risk factors for non-adherence and/or non-persistence and proactively engage with patients to address concerns. This guide highlights critical aspects to encourage engaging discussions with your patients, with the overall aim of enabling patient-centric care.



This discussion guide is dedicated to patients identified as having **any** of the specified **risk factors** for **non-adherence** and **non-persistence** at the time of diagnosis

If you wish to read more about the evidence demonstrating the links between risk factors presented here and non-adherence and/or non-persistence, please see [Okada M, et al. *Ophthalmology*. 2021;128:234-247.¹](#)

How to approach discussions with your patient who may be at risk of missing and/or stopping treatment

- **Confirm whether the patient meets the at-risk profile for the relevant risk factor(s)**
Check whether your patient shows any of the listed signs or has any of these indicators; if so, they may be at risk of non-adherence and/or non-persistence.
- **Address areas of concern for the patient**
Talk to your patient about their concerns, the support that is available and how a treatment management plan may help.
- **Explain the course of nAMD and remind them of the long-term benefits of treatment**
Ensure the patient clearly understands their disease, what may happen in the absence of treatment, and therefore the importance of adhering to their treatment plan. Encourage the patient to have an open and honest dialogue with you and your team so you can support them and answer any questions they may have.



Identifying patients at risk of non-adherence and/or non-persistence: Initial discussion questions

If you are concerned that your patient may be at risk of non-adherence and/or non-persistence, please consider these five areas that can result in a higher risk for patients to become non-adherent and/or non-persistent. Their answers will highlight which risk factors the patient may have and direct you to the relevant section of this Discussion Guide, which will help steer your conversation. Remember, patients may have more than one risk factor, so multiple sections may be relevant.

1. Do you feel you have a good understanding of your eye disease?

- a. Yes *(please continue to question 2)*
- b. No *(please continue to question 4, then go to section 3 if no other risk factors are identified)*

2. Do you feel you have a good understanding of your treatment, and are you comfortable with the frequency of your appointments?

- a. Yes *(please continue to question 3)*
- b. No *(please continue to question 4, then go to section 3 if no other risk factors are identified)*

3. Do you understand that your treatment will be long-term in order to adequately manage your eye disease and prevent your vision from deteriorating?

- a. Yes *(please continue to question 4)*
- b. No *(please continue to question 4, then go to section 3 if no other risk factors are identified)*

4. Do any of the factors listed affect your ability to follow your treatment schedule?

- | | |
|--|---|
| a. Feelings of anxiety or depression | b. Your age (is patient >90 years of age?) |
| i. Yes <i>(please go to section 1)</i> | i. Yes <i>(please go to section 2)</i> |
| ii. No <i>(please continue to question 5)</i> | ii. No <i>(please continue to question 5)</i> |
| c. Unsure that treatment is benefitting you | d. Insufficient help (from caregiver) |
| i. Yes <i>(please go to section 3)</i> | i. Yes <i>(please go to section 4)</i> |
| ii. No <i>(please continue to question 5)</i> | ii. No <i>(please continue to question 5)</i> |
| e. Forgetfulness | f. Difficulty in visiting the clinic |
| i. Yes <i>(please go to section 5)</i> | i. Yes <i>(please go to section 6)</i> |
| ii. No <i>(please continue to question 5)</i> | ii. No <i>(please continue to question 5)</i> |
| g. Fear of treatment being limited/switched
(e.g. reimbursement challenges) | |
| i. Yes <i>(please go to section 7)</i> | |
| ii. No <i>(please continue to question 5)</i> | |

5. Do you have any other concerns or fears? If so, what are they?

Please direct to the applicable sections if the following key words/terms/behaviours are mentioned or identified:

Risk factor	Anxiety and depression <i>Go to section 1</i>
Key words	Sad or unhappy, Worried, Anxious/stressed, Lonely, Scared or frightened

Risk factor	Higher age <i>Go to section 2</i>
Key words	Too old, Unwell or ill (with other conditions)

Risk factor	Patient perception of lack of benefit or stable disease <i>Go to section 3</i>
Key words	Angry, Unsuccessful, Vision is not improving

Risk factor	Caregiver burden <i>Go to section 4</i>
Key words	Alone, Burden

Risk factor	Forgetfulness and cognitive challenges <i>Go to section 5</i>
Key words	Confused, Disoriented

Risk factor	Challenges in clinic attendance <i>Go to section 6</i>
Key words	Travel concerns, No transport, Long distance

Risk factor	Access to treatment <i>Go to section 6</i>
Key words	Financial worries, Insurance concerns

If no risk factors are identified, your patient may continue to their usual appointment.



1. Confirm whether the patient meets the at-risk profile:

- Signs of depression – continuous low mood or sadness, feeling hopeless and helpless, moving or speaking more slowly than usual, changes in appetite or weight, or lack of energy²
- Signs of anxiety – feeling restless or on edge, being irritable, getting tired easily, or having difficulty concentrating³
- Possible confirmation of depression and/or anxiety by a screening questionnaire conducted by a primary care provider or psychologist (see Appendix I)



2. Address areas of concern for the patient:

The patient:

- is depressed about the disease** – there is some evidence to suggest depression improves with the number of anti-VEGF injections; patients have shown to be cautiously optimistic as it becomes apparent that treatment is helping to slow deterioration of their vision^{4,5}
- is scared about the anti-VEGF treatment (and shares examples of specific fears)** – it has been shown that patients prefer a treat-and-extend regimen, as they know when they will be receiving an injection, allowing them to plan better, which can reduce their anxiety.⁶ Inform them that they will not see the needle coming into the eye and provide very specific information before they start the treatment with regard to the success rates of anti-VEGF treatment in reducing the risk of becoming blind in the future. Highlight that treatment complications, such as infection, are rare and that many patients report treatment to 'not be as bad as they thought it was going to be' after their initial injection. It may also be helpful to mention that the need for repeated injections is often an indication that the treatment is effective, rather than an indication of treatment failure.



3. Explain the course of disease and remind them of the long-term benefits of treatment:

- nAMD is a condition that requires ongoing treatment; it is important to reiterate that attending their planned appointments is crucial to help patients improve and/or maintain their vision, allowing them to carry on doing the things that they enjoy



1. Confirm whether the patient meets the at-risk profile:

- a. Patient is >90 years old with/without other health concerns^{1,7}



2. Address areas of concern for the patient:

The patient:

- a. **is of older age and in general ill health** – there is evidence indicating that treatment regimen flexibility (e.g. 8-week treatment intervals rather than 4-week treatment intervals) is advantageous in older patients for a number of practical reasons that may affect them attending the clinic more frequently, including occurrence of localised infections around the eye, systemic infections, fall trauma, or other conditions, as these may alter the patient's priorities⁷
- b. **is concerned that they are too old for treatment to be beneficial** – evidence indicates that the risk of non-persistence with treatment increases per decade of life;¹ however treatment provides the greatest chance for patients of all ages to maintain their vision⁸



3. Explain the course of disease and remind them of the long-term benefits of treatment:

- a. nAMD is a condition that requires ongoing treatment. It is important to reiterate that attending their planned appointments is crucial to help patients improve and/or maintain their vision and reassure the patient that they are not too old for treatment to be worthwhile.⁸ Open communication regarding any additional health conditions that may alter the patient's ability to attend these appointments, or require additional care, is encouraged

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Patient perception of lack of benefit or stable disease/expectation management



1. Confirm whether the patient meets the at-risk profile:

- Signs of poor understanding of disease and/or treatment
- Incorrect or unrealistic expectations about treatment outcomes (e.g. improvement in condition rather than stabilisation of disease)
- Concerns of treatment being ineffective



2. Address areas of concern for the patient:

The patient:

- does not feel well-informed about their disease and/or treatment** – informing and educating patients and their families about their disease and treatment is essential for ensuring they understand the importance of attending their clinic appointments for regular injections⁹
- is concerned that treatment is not improving their vision** – it is crucial to adequately explain the typical disease progression if left untreated, the importance of therapy and the need for frequent intravitreal injections and follow-up visits to ensure vision does not deteriorate further. It is also important to highlight the limitations of treatment regarding vision gains and maintenance, and ensure that patient and treating physician expectations are aligned⁹



3. Explain the course of disease and remind them of the long-term benefits of treatment as well as the limitations:

- nAMD is a condition that requires ongoing treatment; it is important to reiterate that while patients' vision may not return to what it was previously, attending their planned appointments is crucial to help patients improve and/or maintain their vision. Provide the patient with any additional materials or contact details for further support, as available locally. It may be beneficial to show images of how optical coherence tomography can improve as a result of treatment.



1. Confirm whether the patient meets the at-risk profile:

- From the patient's perspective: Signs that the patient is worried about being a burden to family/caregivers (e.g. attending appointments alone and refusing offers of help)
- From the caregiver's perspective: Indicators of impact on family/caregiver day-to-day life



2. Address areas of concern for the patient or caregiver:

The patient:

- expresses worry about being a burden to their family/caregiver** – this is a common concern for patients with nAMD. Anti-VEGF treatment may reduce the burden of care: studies have shown that treatment with anti-VEGF agents via a treat-and-extend regimen reduced hospital visits compared with pro re nata (PRN), as monitoring visits were not necessary. A treat-and-extend regimen has been associated with decreased caregiver burden, including reduction in time and costs.¹⁰ Hospital transport options, where available, may also reduce the travel burden for the caregiver

The caregiver:

- expresses concern about the impact of caregiving on their day-to-day life** – treatment of nAMD with anti-VEGF agents has been associated with caregiver productivity loss, from a time and financial perspective.^{10,11} However, studies have shown that treatment with anti-VEGF agents via a treat-and-extend regimen reduced hospital visits compared with PRN, as monitoring visits were not necessary. Therefore, a treat-and-extend regimen has been associated with decreased caregiver burden, including reduction in time and costs.¹⁰ Hospital transport options, where available, may also reduce the travel burden for the caregiver



3. Explain the course of disease and remind them of the long-term benefits of treatment as well as finding the optimal treatment schedule:

- nAMD is a condition that requires ongoing treatment; it is important to reiterate that attending their planned appointments is crucial to help patients improve and/or maintain their vision. Personalised treatment regimens can help minimise the burden on patients and caregivers by offering routine and predictability. Patient advocacy groups are also available locally and can offer additional support for patients and caregivers.



1. Confirm whether the patient meets the at-risk profile:

- a. Indicators of forgetfulness (e.g. missed appointments, arriving at the clinic on the incorrect day or at the incorrect time)



2. Address areas of concern for the patient:

The patient:

- a. **forgets key information about their disease or treatment, often needing information to be repeated at each appointment** – repetitive education for patients and their families/caregivers about their disease, treatment, and possible complications is essential to ensure that they understand the importance of attending their clinic appointments for regular reviews and injections.^{9, 12, 13} It may be beneficial to record signs of forgetfulness or cognitive challenges in the patient's file to revisit at future appointments, potentially utilising any clinic apps or tech where appropriate. A consent form for those with reduced capacity may be needed



3. Explain the course of disease and remind them of the long-term benefits of treatment:

- a. nAMD is a condition that requires ongoing treatment; it is important to reiterate that attending their planned appointments is crucial to help patients improve and/or maintain their vision. Patient information leaflets may be provided for patients with cognitive impairment so that they have these details to refer to when needed. Families or caregivers should also be present during appointments to ensure all key information is captured.

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Challenges in clinic attendance



1. Confirm whether the patient meets the at-risk profile:

- a. Indicators of problems with travel to appointments (e.g. late arrivals; missed/cancelled appointments)



2. Address areas of concern for the patient:

The patient:

- a. **is not able to easily or conveniently travel to appointments** – treatment burden related to travel time has been cited as a barrier to treatment adherence.¹ If travel barriers are reduced or removed, this may improve the likelihood of patients attending all scheduled appointments. Hospital transport may be a possibility



3. Explain the course of disease and remind them of the long-term benefits of treatment:

- a. nAMD is a condition that requires ongoing treatment; it is important to reiterate that attending their planned appointments is crucial to help patients improve and/or maintain their vision. Patients should be advised of alternative options that may ease their challenges (e.g. support with transport, more convenient clinic locations if possible, home monitoring during stable phases).

Access to treatment

[requires personalisation to the patient and the healthcare environment/location]



1. Confirm whether the patient meets the at-risk profile:

- a. Indicators that the patient may not be able to access long-term treatment (e.g. if reimbursed injection numbers are limited and the patient is not able to cover the cost)



2. Address areas of concern for the patient:

The patient:

- a. **is not able to secure access to continued, regular treatment injections** – treatment costs and consequent challenges with access can be a barrier to treatment adherence. This is more apparent in countries where insurance status impacts access to healthcare, and those where national health policy limits the number of injections that can be subsidised.¹ Overcoming these barriers may be complicated and take time



3. Explain to patients the long-term benefits of treatment, and discuss their options with regards to accessing treatment long-term:

- a. nAMD is a condition that requires ongoing treatment; it is important to reiterate the value of treatment, highlighting that attending their planned appointments is crucial to help patients improve and/or maintain their vision. Patients should be advised of all support options they are eligible for, including local drug assistance programmes.

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Appendix I

Examples of screening questionnaires:

- Hospital Anxiety and Depression Scale (HADS)^{14,15}
- Patient Health Questionnaire-2/-9 (PHQ-2/-9)¹⁶
- Generalized Anxiety Disorder 2-item/7-item (GAD-2/-7)¹⁷

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The nAMD Barometer Programme is managed by clinical leaders in ophthalmology as well as representatives from the IFA, IAPB and Bayer. The activities of the nAMD Barometer Programme are funded and facilitated by Bayer where the scientists and representatives from IFA and IAPB retain decision authority to the research scope, methods, analysis of findings and dissemination of the outputs of the nAMD Barometer Programme.

