



Communication strategies to improve adherence in neovascular age-related macular degeneration (nAMD) treatment

As part of the nAMD Barometer program, 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.





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

Patient understanding

- A. Do you feel that you have a good understanding of your eye disease? ☐ Yes ☐ No
- B. Do you feel that you have a good understanding of your treatment? ☐ Yes ☐ No
- C. Are you comfortable with the frequency of your appointments? ☐ Yes ☐ No
- D. Do you understand that your treatment will be long-term in order to adequately manage your eye disease and prevent your vision from deteriorating? ☐ Yes ☐ No

If the patient answers 'No' to any of the above questions, see **Section 1: Patient perception of lack of benefit or stable disease**. Even if patient understanding is good, it is still important to identify other potential risk factors to non-adherence and non-persistence (please continue to question E).

Identifying additional risk factors for non-adherence

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

- ☐ Feelings of anxiety or depression (**see Section 2**)
- ☐ Insufficient help (**see Section 3**)
- ☐ Forgetfulness (**see Section 4**)
- ☐ Difficulty in visiting the clinic (**see Section 5**)
- ☐ Fear of treatment being limited/switched (**see Section 6**)

F. Do you have any other concerns or fears?

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

Key words	Go to section:
Angry, Unsuccessful, Vision is not improving	Section 1: Patient perception of lack of benefit or stable disease
Sad or unhappy, Worried, Anxious/stressed, Lonely, Scared or frightened, Fear of injection	Section 2: Anxiety and depression
Alone, Burden	Section 3: Caregiver burden
Confused, Disoriented	Section 4: Forgetfulness and cognitive challenges
Travel concerns, No transport, Long distance	Section 5: Challenges in clinic attendance
Financial worries, Insurance concerns	Section 6: Access to treatment

If the patient is identified as having any or multiple risk factors for non-adherence and non-persistence listed above, it is important to continue conversations related to these specific risk factors over one or multiple visits using the relevant sections to guide the conversation.

Identifying the most important risk factor to address non-adherence and non-persistence will help to prioritize which risk factors to discuss with the patient.

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



[Section 1](#)

[Section 2](#)

[Section 3](#)

[Section 4](#)

[Section 5](#)

[Section 6](#)

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 injections¹
- 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 aligned¹



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:

- 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. 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)
- b. 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:

- a. **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.⁷ Hospital transport options, where available, may also reduce the travel burden for the caregiver

The caregiver:

- a. **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.^{7,8} 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.⁷ 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:

- 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. 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.^{1,9,10} 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





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.¹¹ 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.¹¹ 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 programs



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Appendix I

Examples of screening questionnaires:

- Hospital Anxiety and Depression Scale (HADS)^{12,13}
- Patient Health Questionnaire-2/-9 (PHQ-2/-9)¹⁴
- Generalized Anxiety Disorder 2-item/7-item (GAD-2/-7)¹⁵

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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.](#)





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