

Management of daily ANCA-associated vasculitis (AAV) self-care needs:

A suite of new online resources

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BACKGROUND / INTRODUCTION

AAV is a rare, severe small vessel vasculitis with a relapsing remitting course affecting multiple organs leading to long term morbidity due to cumulative organ damage and high risk of mortality.

Standard of care treatment is combination of immunosuppressant therapy with high dose glucocorticoids which are reduced over time. Maintenance treatment for several years is generally needed.

AAV patients are often challenged in managing their self-care needs without support, and in addition have poor quality of life and reduced functional status.

Lack of effective disease education may be a barrier to successful self-care approaches.

This project aimed to understand patient needs and then provide online support materials to help improve self care.

METHODS

AAV Patient associations and their members from several countries gave critical insight on patient needs. This insights were collected through workshops conducted with patient association heads, patients and their carers.

A literature search examined the clinical evidence around educational needs and self-care approaches in autoimmune inflammatory conditions including AAV. This was then synthesised into online self-care material.

RESULTS

The needs outlined by the patients focused attention on priority issues and the literature review provided guidance on effective approaches to meet these self-care based needs.

Five particular needs-based self-care resources were developed and are available online at www.myANCAVasculitis.com.

Result 1 – Provision of information on the disease and treatments with initial remission induction and maintenance.

The digital platform provides an information resource which is easy to understand dedicated to anybody with or effected by AAV.



The acute disease at diagnosis and relapse is a particular concern to patients so practical tips are provided on how to spot the key characteristics of AAV. With different treatments available, general advice is supplemented with treatment-specific information on administration and possible side effects. Active monitoring may help patients to better understand and advice is given to the patient on how to feel more in control and organized around treatment decisions.

However, the online resource signposts the patient back to their caring physician at all times (and supports the patient with suggested questions to ask) and to their local country patient organisation for face to face support.

Result 2– Realistic goal setting

Many people with AAV find that setting goals helps them become a more active participant in their disease management by giving them short- or long-term targets to aim for.



Result 3 – AAV disease monitoring - Self Management requests or recommendations by the doctor are practical and deliverable e.g. monitoring blood pressure



If your doctor recommends it, you may also wish to actively monitor your AAV by checking your blood pressure regularly (such as once a week) using a blood pressure monitor and get in touch with your doctors if you notice ongoing changes.

Result 4 – AAV – Self Management Checklist / Action plan

This Action Plan can help the patient to stay organised and manage their daily AAV self-care needs. The Action Plan checklist below can help reduce the impact of AAV on everyday life

How can I manage my self-care needs?

It can be difficult to manage your daily AAV self-care needs and challenges. Staying organised and on top of these tasks can help lessen the impact of AAV and improve your overall health and wellness.

Self-care can involve requests from your doctor, as well as steps you need to take to manage your AAV between visits.^{1,2}

- Take medicines as prescribed by your doctor
- Try to take steps to avoid infection (such as washing hands) and get vaccinated when needed
- Keep up with all doctor visits and health-related exams
- Track and report progress with your doctor, such as positive changes, symptoms and treatment side-effects
- Report any serious concerns to your doctor promptly
- Try to eat healthy foods to support overall wellness
- Stay active and try to maintain valued roles (parenting, work, hobbies)
- Adjust your routine when needed, and consider what you can do to manage symptoms, treatment, and other self-care needs

Result 5 – Maintaining a diary

Patients can also use a diary to write out questions for their doctor along with anything else that they would like to discuss with their health care professional at their next appointment.



You can write in your diary each day or just use it when your circumstances change. Topics that may be useful to include are your symptoms, treatment, side effects, and AAV's impact on your everyday life and lifestyle, as well as any other health issues that seem unrelated to the disease.

SUMMARY / CONCLUSIONS

Living with AAV is a challenge to patients and this project developed, with patients, online self-care resources which aim to help educate and empower people living with AAV.

These are simple to implement actions available to people suffering from a chronic autoimmune illness such as ANCA-associated Vasculitis to help fulfil their self-care needs. These can either be requested by a patients health care professional or can be implemented self-driven by the patient.

Self-care tools are simple and practical and include

- Information on the disease and treatment
- Goal Setting
- AAV disease monitoring - e.g. measuring blood pressure
- Action Plans or Checklist
- Maintaining a diary

Attention should always be paid to a close dialogue between the patient and their health care professional to align and to agree on Self-care tools to be used. Country patient associations are signposted to provide invaluable patient to patient support.

REFERENCES. Detailed References and footnotes are available under <https://www.myancavasculitis.com/treatment-self-care/>

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