A patient's perspective on education

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Overview

1. **Introduction: My journey**

2. **Why education matters – knowledge as the power to...**

3. **How to become an educated patient**

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My journey as an arrhythmia and device patient (1999 – today)

- **34 y., first official diagnosis at 17.**

- **8 catheter ablations** (permanent SA-node reentry-tachycardia, AVNRT, atrial flutter, 3 ectopic atrial tachycardia, AV-node ablation).

- **Antiarrhythmic drugs** (Metoprolol, Atenolol, Nebivolol, Verapamil, Flecainide, Propafenone, Dronedarone, Amiodarone, Sotalol).

- **8 pacemaker surgeries** (dual-chamber, epicardial leads, 100% AP/VP).

- **Superior vena cava syndrome following SA node ablations, corrected by open-heart surgery.**

- **Anticoagulation** (Warfarin with home monitoring, now Eliquis).
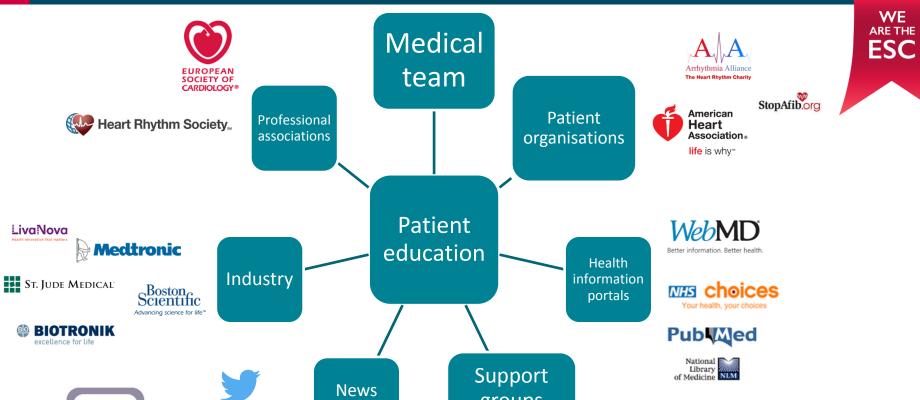
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Why education matters – knowledge as the power to...

- **Reduce the feeling of helplessness and of losing control, allows me to play an active role in decision-making processes.**

- **Overcome fears/anxiety.**

- **Frame realistic expectations of treatment outcomes/avoid disappointment.**

- **Stay positive.**

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Medical team

Professional associations

Patient organisations

Industry

Patient education

Health information portals

News channels

Support groups (on/offline)

www.escardio.org/EHRA

My wish list for EHRA

- Create a "Find a heart rhythm specialist"-database for Europe.

- Promote/award prime examples of patient education initiatives, organisations, educational programs and foster exchange between these.

- Include patient education in Cardiostim/Europace (poster sessions, How to-sessions, awards).

- Europace Journal: include patients in the reviewing process (like BMJ) & include summaries of papers for patients.

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Thank you very much for your attention!

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WE ARE THE ESC

EUROPEAN Heart Rhythm ASSOCIATION
A Registered Branch of the ESC

EUROPEAN SOCIETY OF CARDIOLOGY®

How to become an educated patient – the hurdles

- Wealth of information, but how do I find reliable sources?

- Lots of information, support forums etc. in English, on the national level this varies.

- Access to scientific data is limited for patients, study outcomes are not published in lay-language.

- How do I find the "real" expert?

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