

Should you take calcium channel blockers for Raynaud's from scleroderma? Facts and decision aid

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What is Raynaud's?

Raynaud's is a disease in which the small blood vessels narrow and slow the flow of blood to the skin. The most common sign is cold, pale (white), numb fingers and toes. As blood flow returns, the fingers and toes may be painful. These attacks usually happen when a person is cold and may also happen if a person has stress or is taking certain drugs.

There are two types of Raynaud's: primary and secondary. Primary Raynaud's is the most common and has no known cause. It often happens in women aged 15 to 35 without any other symptoms. Secondary Raynaud's happens along with other conditions such as scleroderma. Scleroderma is a disease where skin, joints, and blood vessels are replaced with thick tissue. It is thought to happen when the body's immune system attacks its own tissues. It usually happens in women or men older than age 35.

A painful attack of Raynaud's from scleroderma sometimes happens and then gets better on its own. If Raynaud's gets worse and is not treated, it may result in:

- damage to blood vessels
- ulcers or sores on toes and/or fingers
- in the worst cases, it could lead to gangrene in fingers and toes that need to be removed with surgery

What can you do on your own to manage your disease?

- Limit caffeine, nicotine (tobacco)
- Keep warm
- Avoid stressful situations

What treatments are used for Raynaud's from scleroderma?

The treatments may be used alone or together. The common (generic) names of treatments are shown below.

- Captopril
- Nifedipine
- Nicardipine
- Felodipine
- Prostacycline
- Nitroglycerine
- Diltiazem

What about other treatments you may have heard about?

There is not enough research about the effects of some treatments. Other treatments do not work. For example:

- Biofeedback
- Anti-platelet treatment
- Ketanserin
- Aaftidrofuryl
- Clofenil
- Alpha blockers
- Dazoxiben
- Beta blockers

What are your choices? How can you decide?

Treatment for your disease will depend on your condition and your doctor's advice. You need to know the good points (pros) and the bad points (cons) about a treatment before you can decide.

When your doctor offers you a choice of calcium channel blockers, such as nifedipine, this guide may help you.

Step 1: Be clear about the choice

What are the options?

Should you take calcium channel blockers, such as nifedipine?

Calcium channel blockers are pills that are taken every day.

When does this choice have to be made? Check one

- Within days Within weeks Within months

How far along are you with a choice? Check one

- You have not thought about it yet You are thinking about the choices
 You are close to making a choice You have made a choice

Step 2: What do you think of the pros and cons of calcium channel blockers?

The information below is from a review of 6 studies that tested calcium channel blockers in people with Raynaud's from scleroderma. These studies lasted up to 12 weeks.

1. Review the common pros and cons.
2. Add any other pros and cons that matter to you.
3. Show how much each pro and con matters to you. Circle one (*) star if it matters a little to you and up to five (*****) stars if it matters a lot to you.

PROS AND CONS OF TAKING CALCIUM CHANNEL BLOCKERS			
PROS	How much does it matter to you?	CONS	How much does it matter to you?
Fewer painful attacks over 2 weeks	* * * * *	Do not know if there are fewer painful attacks over the long term	* * * * *
Less severe pain during an attack	* * * * *	Side effects: water retention or swelling in the feet, feeling dizzy or light-headed, nausea, headache, flushing, weakness	* * * * *
Drug is safe over long periods of time in other diseases and likely very safe in Raynaud's	* * * * *	Cost of medicine	* * * * *
Other pros:	* * * * *	Other cons:	* * * * *

What do you think of calcium channel blockers, such as nifedipine? Check one

- You are willing to take this treatment
Pros matter more to you than the Cons
- Unsure
- You are not willing to take this treatment
Cons matter more to you than the Pros

Step 3: What role do you want to have in choosing your treatment. Check one

- You prefer to choose on your own after listening to the opinions of others.
- You prefer to share the choice with: _____.
- You prefer someone else to choose for you, namely: _____.

Step 4: Find out what else you need to help you make the choice

Facts	Do you know which options you have?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Do you know both the good and bad points of each option?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Values	Are you clear about which good and bad points <i>matter most to you</i> ?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Support	Do you have enough support and advice from others to make a choice?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Are you choosing without pressure from others?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Certainty	Do you feel sure about the best choice for you?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

If you answered "No" to many of these questions, you should talk to your doctor.

Step 5: Plan the next steps

What do you need to do before you make this choice?

For example – talk to your doctor, read more about this treatment and other treatments.

Step 6: Share your answers on this form with your doctor

It will help your doctor understand what you think about this treatment.

Appendix A: Key Words are Defined

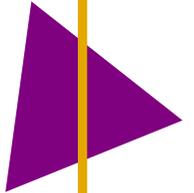
Raynaud's is a disease in which the small blood vessels narrow and slow the flow of blood to the skin. The most common sign is cold, pale (white), numb fingers and toes. As blood flow returns, the fingers and toes may be painful. These attacks usually happen when a person is cold and may also happen if a person has emotional stress or is taking certain drugs.

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Pain varies from person to person. When it is severe, it can limit your daily routines at home and at work. Also, it can get in the way of how you feel in general about your well-being.



Appendix B: Facts and Numbers Behind the Decision Aid

These facts are only for those who want to know more about how the decision aid was made. To make your choice, you do not need to read it.

The following are the data sources, assumptions and calculations used in this decision aid. These are the best estimates based on available data. Data are subject to review as more information becomes available.

The information presented in this patient decision aid was based on evidence referenced in Appendix C (below).

It is assumed that patients who participated in the research studies used as the data sources for this patient decision aid would be similar to patients who would use the decision aid.

Author disclosure: None of the authors or their institutional affiliations can gain financially from the information contained within this patient decision aid.

Reading level: This decision aid is estimated to be able to be understood by patients with less than grade 8 reading level. Readability was calculated using the SMOG index.

This patient decision aid meets the following draft standards of the IPDAS Collaboration © 2004:

- Used a systematic development process
See credentials of review team. Physician & consumers revised the decision aid (see list of developers). The needs assessment and review is underway with patients and physicians who were not involved in its development.*
- Provided information on the condition, options, and their outcomes
health condition, options (including doing nothing), natural history, procedures involved, positive & negative features of options, probabilities of outcomes.
- Presented probabilities of outcomes (benefits and harms)
Uses event rates, comparing same denominator, same period of time and balanced frames. Describes uncertainty around probabilities (our best guess), using more than one method (numbers, words, diagrams). There is no tailoring of probabilities to individual risk categories. Refers to reference of source of probabilities.
- Clarified values and suggested ways to communicate values with the practitioner
Describes features and physical, emotional, and social effects (Summary and glossary). Asks people to think about which positive and negative features matter most using balance scales and rating exercises. Suggests patient share their worksheet with the practitioner
- Used personal stories of how others' made their decision
Not included.
- Guided or coached in deliberation and communication.
Uses step-by-step process. Uses worksheet and suggests sharing it with practitioner.
- No coaching offered but could be used with a coach.
- Disclosed conflicts of interest
Funding source disclosed for development and distributing. Discloses conflicts of interest of authors and affiliations.
- Delivered the decision aid on the internet. Currently available only as a PDF on the internet.
An interactive internet version is under development.*
- Balanced the presentation of options.
Compares positive and negative features with similar detail and emphasis (font, order, display). Field testing for balance is underway.*
- Used plain language.
Plain language specialist reviewed the decision aid and readability level < grade 8 by SMOG.
- Based information on up-to-date scientific evidence
pending_ Evaluated its effectiveness; currently being evaluated.*

* underway in CIHR grant 2004 (Brehaut, Tugwell & O'Connor)

Appendix C: References

Furst DE, Pope J, Clements P, Ottawa Methods Group. Systemic Sclerosis. In: Tugwell P, Shea B, Boers M, Brooks P, Simon LS, Strand V, Wells G. *Evidence-based Rheumatology*. London: BMJ Books, 2004.

Thompson AE, Shea B, Welch V, Fenlon D, Pope JE. Calcium-channel blockers for Raynaud's phenomenon in systemic sclerosis. *Arthritis Rheum*. 2001 Aug;44(8):1841-7.