



Rheumatoid Arthritis Patient Education

1. What is Rheumatoid Arthritis? What are the common symptoms?

Often as the term arthritis is revealed, views start to pour in from all corners with near and dear ones describing their take on the disease. Often considered as disease of elderly, you are left to ponder why it has happened to you? Where did you go wrong to this disease of “old”. Everyone will feed you with their “general experiences” and adds to dilemma. Remember disease of elderly called osteoarthritis is not same as Rheumatoid Arthritis.

It is important to understand your disease as ignorance here won't be a bliss. Take command and be the architect of your life. Knowledge about disease helps you allay your fear to some extent

Rheumatoid arthritis is an autoimmune disease which means there are cells in the body which are meant to protect you from foreign invasion like infection, begin to consider your own body as an alien for eg your joints. They start attacking your joints. Imagine police who were supposed to keep criminals in check but start attacking civilians.

The disease generally affects small and large joints in a symmetrical fashion and is characterised by pain and swelling in these joints. You may suffer from morning stiffness which can last beyond thirty minutes.

Misfiring of your immune cells may not be limited to joints and you may get other manifestations in the form of long standing cough when lungs are affected or nodules or dryness of mouth or eyes. Knowing your disease well will help you tackle it better because there are so many treatment options available. Important is timely diagnosis and management.

Treatment options are plenty but important is to take medications timely and follow doctor's advice carefully. We may not cure you but we can help you achieve disease control so that you feel like a healthy individual.

2. What symptoms should alert you?

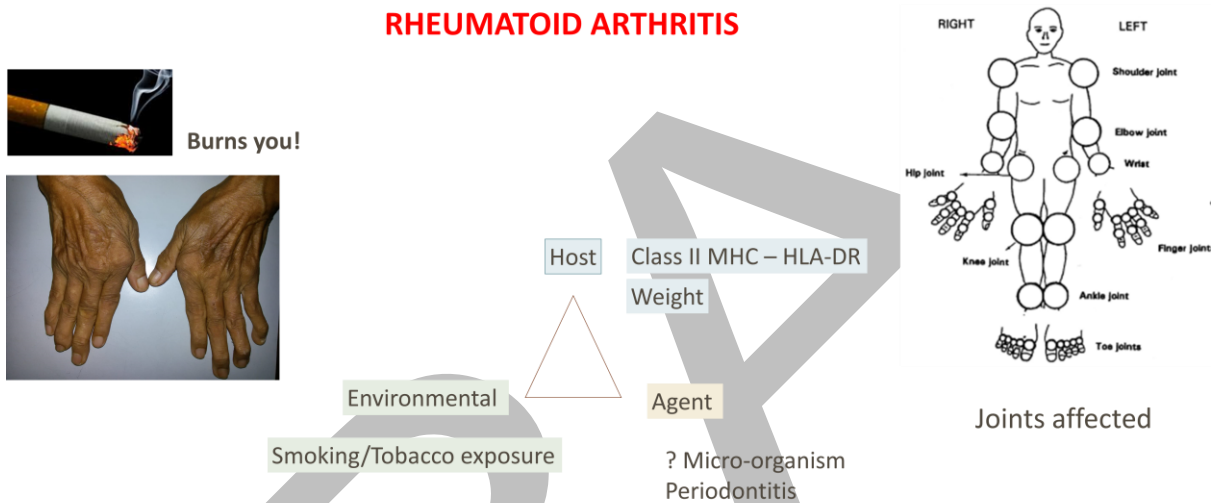
- a) Five or more joints involved
- b) Same joints involved on both sides
- c) Disease duration more than six weeks
- d) Early morning stiffness of more 30 minutes or stiffness after a period of rest
- e) Presence of other symptoms like nodules or dry cough or breathlessness
- f) Dryness of mouth or eyes or-tingling/numbness or an ulcer

3. How common is the disease?

We don't have studies spanning the entire nation looking at disease prevalence but remember this is the most prevalent autoimmune arthritis in India and world. It affects females more commonly and can affect any age group from children to adults to old aged individuals. It is seen in one in hundred to one in thousand individuals.

4. What causes RA? Can we prevent it or predict it?

There are multiple reasons which have been explored but none alone can explain this complex disease. Genes, infection and environmental factors all play a role. The triangle below is an overview but remember mere presence of these genetic factors will not give you RA or predict RA. Smoking definitely increases risk, worsens the disease and dilutes the effect of the medications. So it is important you quit smoking before disease makes it difficult for you to even hold a cigarette in your hand.



5. What all joints can be affected?

It can affect small and large joints of the body as highlighted in the figure. Small joints include wrist, fingers, toes classically and large joints refer to shoulder, elbow, knee. Hip is less commonly involved. Cervical spine can be affected as well and another joint in the neck called cricoarytenoid can be affected resulting in hoarseness of voice. Occasionally you may notice pain while chewing indicating involvement of temporomandibular joint.

6. Is it familial? Will my kids or siblings suffer the same fate?

There is a genetic component to disease but it does not really predict the chances your relative might get the disease. In fact, even in identical twins, chances of getting RA in other twin, if one has the disease, is only 15-20%. You may question yourself that no one else in your ancestors had this disease then why you?

So it is not necessary that you will get a positive family history or you will transfer the disease to your future generations.

7. Does diet influence disease activity?

Remember, you can have anything you like but if you find particular food item(s) which worsen your joint pain every time you consume, you may stop it. Else there are no dietary restrictions. You can have protein and citrus fruits as much as you like! But remember it is important to manage weight. Ask your doctor what would be an ideal weight for your height.

8. Is there role of stress?

Some people recollect a period of stress or trauma before the advent of these symptoms or may relate to disease flare during periods of stress. It is not clear whether such stressful events are more common or is it a recall bias. **There is a famous-quote** by Friedrich states **he who has a why to live** can bear almost any how.

9. What is the natural course of the disease?

It is difficult to predict course in an individual patient but with increasing advancement in Rheumatology, targeted therapy has helped to achieve remission (temporary cure). It is pertinent to start treatment early and adhere to suggestions by the treating doctor. Discuss the treatment options available. Often the treatment is started with methotrexate which works in six to seven out of ten cases. Depending on the drug chosen, you need to give time before they start showing their effect. Discuss with your doctors what to expect. There will be days when disease may flare but remember like in diabetes, there will be times when sugar can go high despite medications, joint pain may increase but can be controlled. Or take another example of hypertension – there can be fluctuations but it can be regulated. Flare of disease means increase in joint pain. Sometimes stress or an infection can flare your disease. Thus, course can be fluctuating but remember it is often darkest before the dawn. Only in 10-15% of the patients, disease may be resistant. But with increasing awareness, early diagnosis and treatment, large armamentarium of drugs, scenario is improving.

There can be stiffness in the morning or after period of rest but getting back into your daily routine will take away the stiffness. So don't wait for it to go and then start your day. Do the other way round – start your day and stiffness will go away

10. How to tackle disease flare?

It is important you continue the medications as suggested. Sometimes it can be easily tackled with few days of painkillers. Continue to do your exercises gently. Take warm water bath. Meet your doctor.

11. Is it life threatening?

It can involve multiple other organs other than joints but with good care and compliance for medications, life expectancy is almost same as general population.

12. Myths around RA?

Few important things to note is

a) A good healthy lifestyle is always important but it takes multiple factors including genes, environment before the disease manifests.

- b) It is not contagious
- c) It is not a disease of “old”
- d) The drugs, being immunosuppressive, can have side effects but remember disease is more disabling. Your doctor will always monitor your side effects and analyse blood tests to monitor same.
- e) Often you would be told or a doubt may come to your mind – “Will my body get used to of drugs or will I be dependent on them of life?” Yes, but is it not better than being dependent on others? Take command of your life
- f) Diet has already been discussed – You might be left with only few items to eat if you follow everyone’s advice! Eat as much protein as you like.

13. What are the medications available and their side effects?

There is a long list of medications available as highlighted in following table along with their side effects profile. You should be aware but not scared of adverse events as it is important to have knowledge about drugs that you might be taking. This will help you understand and adopt them better. Often it is the wrong dose or a drug interaction that does more harm. So a doctor will do your baseline tests before deciding any one of these medications for you and will follow you up with relevant tests routinely to monitor the side effects. So it is important that you spend time with your treating doctor to understand more about them.

Disease modifying anti rheumatic drugs or DMARDs				
S.No	Class	Example	Utility	Common side Effects
1	Conventional DMARDs (cDMARDs)	Methotrexate*	They reorganize your immune system to stop attacking your own body; takes time to act (4 to 12 weeks) but have long term effect and prevent damage	Nausea, Vomiting, skin photosensitivity or rash, hair fall, oral stomatitis, low cell counts, transaminitis
		Leflunomide*		Nausea, vomiting, diarrhoea, alopecia, skin rash, headache, hypertension, paraesthesia, transaminitis
		Sulfasalazine		Headache, Skin rash, Dyspepsia, flu like symptoms, Cytopenia, reversible oligozoospermia
		Hydroxychloroquine		Skin rash, hyperpigmentation, gastritis, myopathy, dizziness, vision abnormalities
		Steroids	Hypertension, Diabetes, cataract, weight gain, osteoporosis, gastritis	
2	Biologics	Infliximab, Adalimumab*, Etanercept*, Golimumab	They reorganize your immune system to stop attacking your own body similar to cDMARDs but faster acting; relatively expensive	Infections, infusion reaction, rash, heart failure, demyelinating disease, autoimmune disease
	Anti-TNF			
	BCDT	Rituximab		Infusion reaction, hypertension, infection, Cytopenia, angioedema, asthenia, pulmonary disease, chills, insomnia
	IL-6 inhibition	Tocilizumab		Dyslipidaemia, transaminitis, infusion reaction, hypertension, Cytopenia, nasopharyngitis
	JAK inhibitor	Tofacitinib (oral)	Infection, nasopharyngitis, headache, Hypertension, Skin rash, diarrhoea, anaemia, dyslipidaemia	

*Avoid if planning pregnancy or pregnant or breast feeding

14. How long do I need to take medications?

This is another difficult question and there is no straight to answer. Generally, it is lifelong like ~~any~~ diabetes or hypertension. But with early diagnosis, treatment and after a period of sustained remission, it is possible to come down to minimum number of drugs(s).

15. What is remission or low disease activity?

When a doctor uses the term remission or low disease activity, what he or she tends to convey is that your disease is under control with no or minimal pain or swelling in the joint and normal blood reports. He uses certain disease activity indices besides his own experience to decide how active the disease is.

16. Do Ayurveda or naturopathy or homeopathy work?

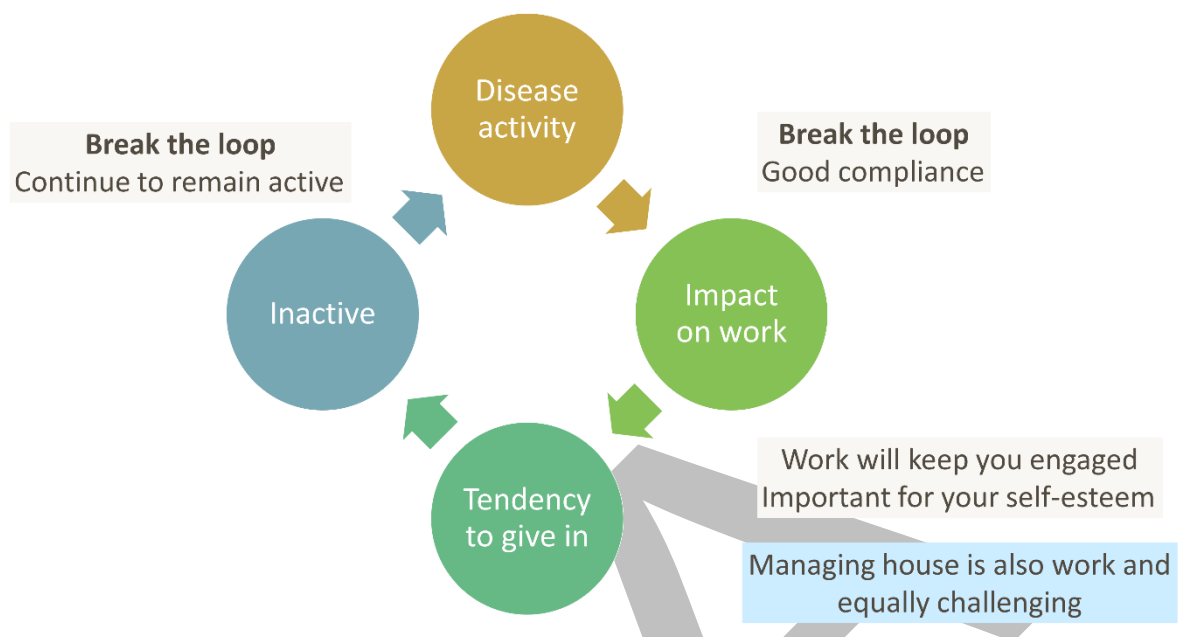
It is good to discuss with your doctor and inform him if you are taking complementary medications so that drug interactions can be kept in mind. Discuss your experience with the doctor or involve him in taking a shared decision.

17. What is the importance of physiotherapy?

Entire world is realising the importance of yoga and physiotherapy in general. It boosts your immune system, unnerves and relaxes it. In fact, it forms the most important part of your treatment. It is free of cost but needs lot of discipline as we often neglect this mode of treatment. Yoga, aerobics, deep breathing exercise are all very important. Remember it is not just medications alone which will do wonders for you. They are like oil to your body which is a machine! But a machine would rust even if oil is added unless used well!

18. Can it affect my work?

Yes, there can be effect on your productivity and efficiency and hence affecting your work. Often the disease activity seems to be controlling the same which is quite obvious. There are two ways to combat it – follow your doctor's suggestions and continue working as much as possible as keeping yourself active ultimately helps.



Amplification Loop – stay active to drive away your blues

Meet an occupational therapist who can help you with your work and activities that you do. They will help you adapt and find ways to make you feel productive.

19. How to maintain energy?

Mix up your day with intermittent breaks for rest, exercise as it helps you to distribute your energy. You may feel tired and fatigued and stiff after periods of inactivity but remember the stiffness is transient and it goes away with activity. Lower your targets and gradually upscale them as you achieve them.

20. Should I share or not share?

This is a personal decision. Don't let the physical nature of the disease affect you mentally. Stay strong, share if you want, as discussion helps.

21. Is there a cure?

Recent studies are toying with the idea of "cure". But currently there is no cure but remission or low disease activity with available drugs are achievable. What is most important is timely diagnosis and management.

22. How long will the disease last?

This is another important question which will trouble you more at the onset but sooner or later you will get adapted. Disease tends to last long and the thought can be frustrating but with good compliance and healthy life style, you can lead a constructive life.

23. Does it cause fatigue or low mood?

Yes, it can cause both. Any long standing disease can make you feel so.

Inflammation, chronicity of the disease, medications are some of the factors that can make you feel drenched. But with good disease control and exercise, this can be conquered. Often disease affects the decision taking abilities, more out of apprehension, than disease activity per se.

Channelize your energy well by focussing on things in your hand – adherence, exercise and work. Do not burden your joints with lot of backpack. Remember your goal and family and suddenly you will feel all charged up. Set a target. Socialize, mix up with your friends and family. Feel independent. Keep in mind, arthritis is not your identity, your work, your role in society is your identity.

24. What are other complications I should be aware about?

As discussed briefly, RA can affect other organs in the body but can be picked up and treated. Discuss your symptoms with your doctor. Remember to check your blood pressure, sugar and cholesterol as long standing disease can affect your general health. With good disease control and monitoring, these can be prevented or very well taken care of.

25. Can it affect Pregnancy or can I get pregnant?

Yes, you can get pregnant but discuss your medications with doctor. Drugs like methotrexate, Leflunomide and pain killers in third trimester are contra-indicated. Ideally let your disease go into remission or attain a low disease activity status for six months before you conceive. Monitor fetal growth, take your medication as advised.

26. How can I contribute?

Remember a doctor learns from a patient more than what he learns from a book. He uses this experience to treat every new patient in a better way. World is moving towards personalised medicine. Therefore, exploring and comprehending the disease is important. His responsibility is to treat you and in an appropriate research setting, he needs to improve the care. You can help by participating in such studies after understanding the impact of such studies. This may not help you immediately but your contribution will definitely help in scientific progress. “We are because you are, and since you are, I am”

What is important is need for constant education/discussion with your doctor and need for re-enforcement as chronicity is double edged sword! You may be gaining more experience but might give up. Don't just discuss the joints but share you feel. Be you own architect and design your life around it with available resources. Discuss with us and with fellow patients. Take a proactive role and maintain good quality of life.