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19th May, 2008

Dear Natalie,

NRAS Response to Appraisal Consultation Document
Sequential use of Adalimumab, etanercept and Infliximab for the treatment of RA

I would like to thank NICE for the opportunity comment on the above ACD.

I would first of all like to state that NRAS supports and endorses the joint submission by ARMA and I do not propose to repeat all the points made in that submission here, however I do wish to comment on the questions asked in the ACD from the patient perspective.

i) Do you consider that all of the relevant evidence has been taken into account?

1. There is clearly a lack of evidence available of people returning to DMARD therapy following use of an Anti-TNF because this would be a retrograde step, given current clinical practise. With this ACD, we are not addressing the clinical and cost effectiveness of a new therapy, the Appraisal Committee are recommending not to switch to a second TNF on grounds of inefficacy, in spite of the fact that this has been successful clinical practise in the UK for a number of years. As a patient, I have to have faith in and trust the best advice of my Rheumatology Consultant and the team, and when they recommended that I switch from the first

TNF to a second and a year and half later, to a third TNF, I did so on the grounds that this was the best medical advice and in the knowledge that I had a 70% chance of responding (pretty good odds to someone with a destructive, disabling and painful disease like RA, and odds which I chose to accept). The option of going back onto DMARDs on which I had already failed and to have to start taking steroids again, which I have managed to do without for the last four years entirely due to Anti-TNF, was simply not even discussed as it is not a course of action which any rheumatologist would have considered a viable option by comparison with going onto a second or third TNF – it would make no sense at all. This point was made time and time again by the Clinical Experts at the Review.

2. I believe that there has been a fundamental failure on the part of the Committee to appreciate just how complex and individual a disease RA is. There are a number of clinical subsets of this disease and we don't know why one person responds to a particular biologic and the next one doesn't. This is why it is so vital to have many treatment options in the patient pathway, a view held by the entire rheumatology community, not just the patients. If you are diagnosed with RA at age 25 and are unlucky enough to have severe, progressive disease, you have many years to live, in spite of the fact that your life expectancy may be reduced, and you will need many options available to you over the years. It is therefore with great disappointment and dismay that we see our options diminishing rapidly.

3. I am concerned that the committee display a lack of interest in patient quality of life evidence. As a patient expert for many years now, I can confirm that with the exception of the Chair of the various Appraisal Committees I have attended (who does give the patient experts the opportunity to speak), only on one occasion have I or any other patient expert with me ever been asked a question by any other member of the Committee. The majority of the time is spent on health economics, cost effectiveness, the model and clinical data from trials.

4. Rituximab therapy is not suitable for all patients. In particular the evidence that it works in sero-negative patients (those that are negative for anti-CCP and rheumatoid factor) is lacking. For example, in the DANCER study the placebo was as effective as rituximab (for ACR20 responses). Therefore, under current NICE guidelines for patients who are sero-negative and failed TNF blockade it is only possible to offer ineffective therapy with potential side-effects. The availability at least of a second TNF for a restricted group of patients would therefore be more logical, more effective (including cost-effective) and safer.

ii) Do you consider that the summaries of clinical and cost effectiveness are reasonable interpretations of the evidence and that the preliminary views on the resource impact and implications for the NHS are appropriate?

1. We agree with the statement in the ARMA response that the over-reliance on the BRAM model to the exclusions of other models is inappropriate. We continue to point out that reduction in HAQ score is not a sensitive enough measure of outcome in this group of patients, most of whom have had the disease for many years and failed on 3 or 4 DMARDs and sustained substantial joint damage.

2. We understand that under the present NICE remit, the wider societal costs cannot be taken into account in the economic modelling, however, we are fully aware of the recommendations by the Health Select Committee in this regard in January this year and feel strongly that this is something which NICE itself should be actively addressing and encouraging government to change the remit. When Dame Carol Black addressed the British Society for Rheumatology annual conference in Liverpool recently, she identified that sickness absence and health related worklessness amounted to over £100 Billion per year, i.e. more than the budget of the NHS.

   Costs of medication represent a comparatively small proportion of direct costs. Indirect costs caused by work disability can be substantially higher than direct costs, particularly in working-age patients. This must now be addressed with some urgency by NICE.

iii) Do you consider that the provisional recommendations of the Appraisal Committee are sound and constitute a suitable basis for the preparation of guidance to the NHS?

In short, NO, for all the above reasons and those covered by our fellow stakeholders.

iv) Are there any equality related issues that may need special consideration?

1. The patients who are sero-negative and Anti-CCP negative are disadvantaged by comparison to those patients who are sero-positive.

2. The patients in the UK are disadvantaged by comparison to other people with RA in Europe and I detail below a comment in this regard by Prof. Paul Emery in his capacity as President-Elect of Eular which we support:

“Dear Sir

One of the remits of EULAR is to ensure there is reasonable access to effective therapies for all patients with arthritic conditions in Europe. The U.K. now has the lowest use of biologics of the Western countries, and also the most restricted and illogical use. Anti-TNF use is restricted until late in disease and if TNF fails have only access to B-cell depleting therapies as switching is not permitted.

This means that biologics will be used at a time when they are less effective and that inappropriate patients will be treated, particularly with B-cell depleting therapy. In terms of its provision of care for these sick patients it would be appropriate to have an overview of UK policy rather than piecemeal approval.

Yours faithfully

[redacted]

It seems ironic that on the 12th May, two british researchers, Emeritus Professor Sir Ravinder Maini and Professor Marc Feldmann, who pioneered Anti-TNF therapies at the Kennedy Institute, have been awarded the prestigious 2008 Dr. Paul Janssen Award for Biomedical Research by an international committee including Nobel Laureates and other world-renowned scientists. One has to wonder what their view of recent NICE decisions would be and what effect these decisions may have on the future of research and development in the UK.

Attached to our submission is a list of comments which have been emailed to NRAS in the last week or two from some of our members and I would be grateful if you could ensure that the Committee do read these comments. They surely describe very eloquently what a negative decision would mean to the half million or so people in the UK living with RA.

Yours sincerely

[redacted]

Enc:

Comments from members on the recent NICE announcements
(includes emails up until 5pm 15th May)

Thank you for sending this information regarding NICE' rejection to approve the use of abatacept for people with severe rheumatoid arthritis, a therapy that could really make a difference to their lives. I suffer with severe rheumatoid arthritis, have already failed on other therapies, and can see that this could relegate me to a lifetime of misery. Please continue to appeal for this decision to be changed.

This is an immoral & devastating announcement for those whose lives are already devastated by this crippling desease, resulting in far more operations & other drugs & treatments being needed.

What is the point of developing treatments to help people in severe pain if they are going to be denied when they really need them?

Anti- TNF's have been a lifeline for me. As a pateient currently on anti-TNF drug treatment(enbrol) I am devastated thaat I could be denied further alternative anti-TNFdrugs aif this one fails in the future.
Anti- TNF's enable me to continue to work and to contribute to society and if I am denied treatment I will become a burden and my contribution as a senior soical worker and child therapist will be severy curtailed.
In addition it could mean that my family could have to care for me, and all this will place far more strain on our health and social systemsand cost far more than the drug itself.

I feel that I have a very bleak and disabling future now and will probably end up being reliant on care services, which could be avoided if appropriate medication is available as needed rather than being denied that appropriate medication.

What right has anybody got to deny anybody the right to a pain free life. I would like to know exactly how many people on NICE who have made this decision actually suffer from severe rheumatoid arthritis. As a suffer, it has been the most devastating and crippling conditon. Sinceit began my whole life style has changed, and with no surrent medication helping I am living each day fearing the next, not knowing how much pain I will be in. Nobody should have to live like this or EVER be denied the chance for a good quality of life through a drug that could help.

The recent announcement by NICE is a retrograde step in not allowing further anti-TNF treatments. Whatever their reasoning is beggars belief.

I have been on Enbrel for 5 years now, but if it did not work for me I would like to think I could change, if not I would probably be in a wheelchair and require costly replacement limb treatment.

This is unfair, unjust and morally wrong to take away a proven lifeline from sufferers who need it to have any quality of life!!!

NICE must be encouraged to think again before destroying the management of their R.A. from people.

These are human beings we are talking about not just Statistics!!

It will have a devastating affect on the hopes of some many suffer's that have seen this drug as a last chance to control this disease

I wonder if any of the decision makers at NICE have RA, do they know how painful it can be - I am OUTRAGED.

miracle "cures" can sometimes stop working and to be denied access to further drugs beggars belief

I am utterly astonished that NICE are to recommend single use only of anti

- TNF therapy, I have RA and have experienced the diminishing effects of Methotrexate, I have always hoped that the use of other drugs such as these would be an option to keep me well and mobile. Living with RA is difficult enough. I I hope that this recommendation is revoked and I will be writing to my MP.

If RA sufferers are not allowed treatment because of cost - how much will it cost for the state to provide care for them when they are no longer able to support themselves. Treatment is allowing me to stay in full time employment for the time being - if I was not allowed this treatment I would not be able to work.

Hi my name is [redacted].. i have had rheumatoid atrhritis for 13 years, i was aged 26 when diagnosed. I have had lots of treatments, none of which worked untill i was given infliximab (remicade) this worked for a short time, i was then taken off infliximab and given adalimumab (humira), which i have to say is working well. I am concerned about the announcement by NICE, as many people who do not respond to one type of anti TNF, need others to try.. if i had no otheer to try i would be in an awfull lot of pain.... i intend to write to my mp as i think that all sufferers of rheumatoid arthrits should be given a choice of treatments.....

"Living with a condition which is not curable is a very traumatic experience; it is only with the hope that good medication can ameliorate RA that gives hope to those who have not succeeded with other medications. The decision to deny sequential Anti-TNF therapy is a breach of the Human Right to life."

By its recent very shortsighted decision, NICE is condeming RA patients already suffering debilitating pain to a future life of unbearable pain, together with the associated social and economic implications.

THIS DRUG WOULD STOP ME SPENDING MONEY IN DIFFERENT DIRECTIONS FOR RELIEF

I am lucky enough to be on a Rituximab phase 3 trial with excellent results. However I know from how depressing, disheartening and painful it is, from the year before I was given Rituximab, when drugs fail to improve the effects of RA. Every RA sufferer should have access to all drugs that are known to be effective, in whatever sequence, which may limit this disease. Perhaps those who make up the NICE board should try wearing the bodysuit (recent press coverage) that mimics the constraints (but not the pain) of RA and then re-evaluate their decision.

As someone willing but unable to work due to R.A., I feel that this government is more concerned with 'balancing the books' than with real patient care. No doubt NRAS and other charities will be forced to take NICE to court, like the Alzheimer's Society, on grounds of discrimination against one section of society. It is truly a "nice distinction"!!

Im not happy with what you said in email about NICE and as im not responding to treatment it looks as if i will be on one of the TNF treatments in two months time

I am appalled that a team of 'experts' can suddenly decide to withdraw a proven drug treatment regime. It will have long reaching effects on a large number of people for whom a range of drugs is vital to control their disease and to enable them have a good quality of life.

I only lasted on Humira for 2 years before side effects stopped my use of it and Infliximab for 2 infusions for the same reason - clearly abatacept is something I would like to try.

As a long term Rhematoid Arthfitis sufferer I am disgusted by the recent announcements from NICE, this is a totally disabling disease and any chance of relief being denied is outrageous.

RA is a frightening illness and anti-TNF drugs (Enbrel and now Humira) have meant the difference to me between being housebound and, now, fully mobile.
To deny people the opportunity for sequential therapy is an outrage and yet another example of bodies such as NICE being out of touch with reality. Don't they speak to RA patients?

Very short sighted. People need access to as many types of treatment as possible as we all respond differently and it is difficult to identify the best treatment without flexibilty. One "bite of the cherry" is unacceptable.

I have been on Humira for the past 3 years, but in the past year the disease has become more active and my rheumatologist is considering the option of switching to another anti-TNF drug: I would be devastated if this were no longer an option, as I have battled with RA for 13 years and, now age 56 and managing to work part-time, would like to be confident that the best drugs for my condition were still going to be available to me in the future.

These recomendations will have a crippling effect on all RA sufferers, it is obsured that a known treatment is to be refused.

i have just read your e mail and i am totally shocked by this news, as a user of etanercet i couldn't think of my life without it as it has made alot of differnce to me and my life style.

This will deny R.A. sufferers the right to a lead a normal life.

I Simply cannot understand the judgement from NICE regarding these drugs. To deny someone drugs that are available and could bring someones RA under control is nothing short of in humane. Having lived with RA for the past 8 years I am fortunate that the Embrel drug I am on is keeping my RA mostly under control and allowing me to work part time in a job that I love, serving the community. Without this I could be condemned to a life of agony unable to work and having to claim benefits. Although the short term costs of the provision of these drugs may seem high the cost to society will be far greater in the long run not to mention the cruel irony to patients who know there is medicine availbale to treat their condition but they are unable to access.

My response is shock and total despair. I have been using one anti-TNF treatment for nearly 7 years now, and it is working well enough, my life has been transformed since I was first given it. However, we know that there is always the option to try something else if I stop responding, and that means that we don't have to rush to change treatment, but to do it in a measured, considered way.

The NICE decision defies logic. Anti-TNF treatment has dramatically reduced the amount its recipients call on the NHS, it means that there will be more bone erosions, more call for joint replacement and for pain relief. And it will also discourage further research in the subject, why should the treatments be improved if they cannot be used.

I cannot believe this decision, and can only hope that my consultant will have the means to find a way round it.

I Simply cannot understand the judgement from NICE regarding these drugs. To deny someone drugs that are available and could bring someones RA under control is nothing short of in humane. Having lived with RA for the past 8 years I am fortunate that the Embrel drug I am on is keeping my RA mostly under control and allowing me to work part time in a job that I love, serving the community. Without this I could be condemned to a life of agony unable to work and having to claim benefits. Although the short term costs of the provision of these drugs may seem high the cost to society will be far greater in the long run not to mention the cruel irony to patients who know there is medicine availbale to treat their condition but they are unable to access.

Anti-TNF treatment has given me my life back and my children their Mum back - the thought that in the future I could be denied further treatment that could help me lead a full life as a working Mum fills me with dread.

having just started anti tnf i would be devestated if this was my only hope

I am dismayed at this announcement by NICE, as a rheumatoid arthritis sufferer, these options have always been a comfort to me.

At 37 my second ant-tnf treatment gave me back some ability to live independently; to wash and dress myself, drive, return to work and my Phd- to remember what it is like to have hope for the future rather than just be someone battling a crippling disease and losing.

Humira has enabled me to continue working, if it ceases to be as effective, without further anti-TNF therapy, I shall have no option but to be Registered Disabled. My husband would have to stop working to care for me, whereas at present, his tax bill more than covers the cost of my treatment!

The NICE guidelines are a way of showing me that i am a second class citizen and condem me to living a life of pain and disability.

I am a patient with Arthritis and feel very strongly about the 'biologic treatments' for theses conditions. I have suffered with arthritis for years and have constant pain and fatigue.
Treatments help but none are as good as the new 'biologic treatments' as many of friends have found relief and have also been able to resume their careers so that is an amazing achievement.
What is the point in developing theses knew treatment if they are left on the shelf rotting.
Surely prevention is better and why do we spend years trying to cure a disease and then not giving the patient the vital treatments.
If all knew cases of RA are started on the new treatments the benefits would out weigh the costs, in health, careers and less drain on society.

The announcement by NICE that sequential use of anti-TNF therapy may be discontinued is hugely worrying to me as an RA sufferer who is now on a second anti-TNF therapy as it may mean that I would be denied a further type of biologic which would be disastrous for me; with these drugs I am able to continue to work full-time and to enjoy a good quality of life and I am certain that I would be incapacitated without them and no longer be able to support myself economically and physically.

Please.. give me the chance to enjoy some of my life,

This is devastating news. I am on my 1st TNF enbrol and the thought of this not working for ever and with no other going to be available life will be sheer hell

This announcement means that 2 years ago when my 1st anti TNf stopped working i would not be on the treatment im on now that has vastly improved my quality of life

How I feel about recent NICE decisions

By firstly refusing to sanction the use of abatacept (Orencia) and subsequently denying the possibility of sequential use of anti-TNFalpha treatments, NICE is condemning thousands of people to a possibly shortened life-span, severe pain, increasing disability and potential multiple joint replacement surgery. The obvious economic consequences of these decisions (loss of ability to work, dependence on state benefits, increased demand on hospital, health care and social services) surely make a powerful case, even on a stand-alone and purely objective financial basis.

Additional information

I write as a person for whom biological treatments came in the later stages of my disease. Having had to give up a personally satisfying and economically viable career, I have spent, cumulatively,
many months in hospital and have undergone thirteen rounds of surgery. Patients in receipt of newer treatments, ie those currently being refused by NICE, are unlikely to follow this unpleasant route. I am appalled to think of the inevitable personal and social consequences of such a closed and unenlightened decision. Finally, having tried several newly-developed drugs

before finding the best biological treatment for me, I can truly say that it has turned my life around.

If my anti TNF treatment was to diminish and I was denied the use of another anti TNF treatment I would have to stop working and live on benefits.

"Outrageous".

It has been demonstrated that RA sufferes who respond well (like me) to an anti-TNF drug, function very well, and are able to continue their careers (in my case, international opera singer), thus allowing a full and rewarding life- I earn a lot and pay high taxes. This saves the government lots of money which would otherwise be spent supporting me. Think about it ?

I am definately in support of the RA organisation fighting NICE for the use of anti-TNF therapies for RA and for NICE to approve drugs that will reduce the risks of severe disablement from RA . Fortunately I have mild RA but that is bad enough when working full time - and I still have yet to find a drug that works.

Im living proof that recent advances of drugs can stop RA, my condition is under control, but It would be devestating, if the options of help are reduced or inhibited.

I am horrified that NICE can even consider these moves. At the moment I am fortunate in that I do not need these treatments as Methotrexate is keeping my RA under control. But I do look to the future when I might need them and I also know of people who are dependant upon them to lead a life that is anywhere near normal.

Anti-TNF therapy (Humira) has transformed my life and if it were to stop working, my inability to try other anti-TNF drugs would be devastating - a life sentence of raging arthritis, debilitating pain and inevitable disability.

Enbrel as made me feel 1oo% better if this fails i would need alternative tnf please NICE RECONSIDER

What a mess these 'NICE' people are !! - To me having been diagnosed nearly three years ok, it is just being discussed with my R/A specialised nurse, and Consultant, this would mean trying to 'level out' my R/A, and help me feel back to a 56 year old, instead of feeling and acting like an 80 year old !!! (no offence to the older generation).

I am alarmed and concerned about the information below. Although it does not affect me directly just now, if this is allowed to go ahead, Scotland may follow . For me this would be devestating. Its hard enough to live with such a degenerative disease without being denied relief from the pain and other related symptoms.

How awful to know that other drugs are available but not to you because you failed to respond to the first drug you were offer, you would not have even choosen the first drug.

I would be quite happy with this decision providing similar restrictions on alternative drug therapy were to be made for people suffering from Cancer, Heart Disease, infact any other chronic illness.

I feel really disappointed and let down that NICE could make such a decision that may have such a detrimental affect to the future well being of Rheumatoid Arthritis sufferers.
I was diagnosed at the age of 23 and the damage I have endured since then is pretty substantial, I've been on etanercept for almost 4 years and the huge difference it made to my life was close to a miracle, I would hate to think that I along with other sufferers will have to go back to a life of joint damage and pain should the drug we are now on may at some stage no longer help us. The fact that the other Anti TNF's out there could keep us well and practically pain free would be denied to us would be a crying shame and basically a huge blot on our quality of life.

For me, since there is a doubt about the efficacy of my first anti-TNF - humira - this is a real kick in the teeth, especially as I can`t take MTX, and rely solely on the humira.

NICE have made a very bad decision in this case. It removes the last chance of hope from people like myself who have to suffer a lifetime of absolute misery with this dreadful disease.!

It would be like seeing all your lottery numbers had come up and then realising you had not entered your ticket into the the draw, Or someone throwing you a lifeline when you are drowning and then realising its not attached to anything.

To me personally, it would mean that there probably isn't a future, all my hopes and dreams would be gone, the chance of a pain free life and to continue working would no longer be a possibility, my home could be at risk, my family could be at risk.. it means there is nothing positive to look forward to

Its turning drug treatment into a game of Russian Roulette and that's unpardonable.

For those of us suffering from RA it is the hope of finding a drug to ease our symptoms
and keep the disease under control that keeps us going, and now NICE has destroyed
that hope by allowing us to try one antiTNF drug only.

As someone who has recently started treatment with an ant-TNF dug with amazingly good results, enabling a return to work etc. I am extremely dismayed that treatment by another anti-TNF drug may not be allowed if the effectiveness of this current drug diminishes.

This is devasting news.I found that I only benefitted for a few weeks from Remicade infusions, so changing to Enbrel, made a huge difference.

No-one who hasn't had this disease, can understand the pain and loss of useful 'life ' that it brings, how can any right thinking person/persons take away the lifeline that is, these drugs, why step back in time?

I really don't know how the government/National Institute of Health can justify witholding treatment to people who need it Its disgusting! My first instinct was to say imagine if they witheld drugs from somebody with Cancer, but I just realised that they actually do that too! Why is money always considered more important than peoples lives? Who are they to play god?

Utter despair… So the view is then 'you've tried one so you can't try any others, goodbye and have a very painful rest of your life' absolutely and illogically outrageous! Playing with peoples lives.

As someone who has been told "you need anti-TNF but we haven't got funding" to "you can have anti-TNF its all right now" to "we've changed our mind and money hasn't influenced us" (who are they kidding?) it s not fair to deny effective treatment to RA sufferers. To even be eligible for anti-TNF in most areas you need to be not responding to established treatments. This decision seems arbitrary, based on cost and condemns RA patients who have had the benefit of an effective treatment to returning to a reduced quality of life. I plan to move to Scotland.....

I am very angry at the thought that yet again people who need long term drug relief are being denied an option should their current drug treatment become diminshed, what are we supposed to do, not have a life!!

Both my brother and my brother-in-law have severe RA and are currently taking Humira. Whilst this is controlling their condition at the moment, it would be devastating if this became ineffective and they were denied alternative
anti-TNF drug. Both my brother and brother-in-law are in well-paid full-time work and contribute substantially into the Treasury through taxes. If they were unable to work, the cost of benefits would far outweigh the cost of treatment as they both have families to provide for. I can't believe that NICE would rather increase the number of severely disabled RA sufferers than permit the relief that these drugs provide.

Yet again, NICE proves not to be - gone are the days when we actually cared about others and cost was secondary.

Why is the government doing this to us; do they not realise they are as good as signing our death warrants as so much pain can and does send a person with so much pain to a place where they no longer want or can live anymore!"

This will affect me drastically i am one of those 47 year olds with RA over 10 years , no treatment as yet has worked for me .
I am at present on Humara, with little or no affect. but keeping going for the 6 months.
I have already reacted badly to etranacept, so this is saying thats it , i'm written off, to end up like mum and greatgrandma, (yeh its the genes that got me).
What a waste, I'm not just a pretty face I have many qualifications and was hoping to be back in the high tax bracket once again.

NICE's decision is inhumane

Thank God I live in Northern Ireland.

I realise that had an alternative to Humira not been made available to me, I would be unable to cope with the basic daily tasks which the able bodied take for granted - and would certainly not have been able to even consider getting back into employment.

I feel that this judgement is very short sighted, and has obviously not been thought through properly. Perhaps the following sentence says what I feel:

If you have a headache and a paracetomol does not work don't you try a nurofen? Surely we have a right to the medicines which can make our life so normal and less painful - if not, why develop them in the first place???

RA is a progressive disease with severe emotional, financial and social ramifications; by placing such a ridiculous and inhumane bar on access to sequential anti-TNF therapy, you are essentially telling chronic RA sufferers to get down on their swollen knees with a begging bowl.

I am extremely alarmed at this announcement, made by whom and do they suffer from this debilitating illness, it's just like saying that if aspirin doesn't cure your headache then you're not allowed to take paracetemol or ibuprofen, CRAZY.

17 years after my RA diagnosis I work full time & live a happy, active life
thanks to Adalimumab. To be told this drug may be the 'end of the road' for me is like being told my life, at the age of 37, may soon be over. For people who no longer respond to traditional DMARD drugs, like myself, anti - TNF therapy is the only option we have left.

This would meen a life of even more pain and possable living off handouts for the rest of may life and at 43 this could mean tex payers will foot the bill.

NICE clearly do not understand that RA is a progressive disease and medication needs to be updated regularly to keep it under control. One drug works for a while then the body gets used to that medication and so a different medication is needed.
Restricting a person to only one type of treatment condemns them to a life of pain when there are medications available to treat the disease.
This attitude is very short sighted and not cost effective at all.

this is an injustice to all RA sufferers, with NICE failing in their duty of care of the sufferer, the outcome will be failing the user under the DDA.

NICE way to cause pain, thanks alot.

I am appalled by this reaction by Nice. I have just been put on Etanercept:it may not work..I then cannot do anything else? Stupidity

I am a lawyer who has benefited from the use of sequential anti-TNF therapy.It has been the difference between being crippled on the sofa day in and day out and being able to carry on with my life. Fortunately or unfortunately, our bodies have an incredibly flexible immune system that adapts to medications after a period of use so that changing up medications from time to time is necessary. To deny a person the opportunity to have their medication changed when it ceases to be effective is to deny that person a productive life ultimately costing our society far more than the cost of medication.

I have just started using Humira in January of this year, the results are life changing for me. If in the future this stops working it would be heartbreaking not to be offered a 2nd Anti TNF Treatment, what are these people thinking. Please feel free to contract me regarding any RA subjects as over the last two years I have become an expert!!.

NICE's announcement re sequential anti-TNF is ludicrous. Most of us have the same reaction to anti-inflammatories and other drugs, they work for a while and then we NEED to change to another drug otherwise NO drugs would benefit any of us.

Taking away the opportunity for people to move from one anti-TNF drug to another if the first fails means that they are more likely to become more severely disabled, as rheumatoid arthritis is a progressive disease, and they will thus require more care, social services, hospital treatments, higher rate DLA and so on, so not only is it likely to ruin their chances of leading a comfortable and fulfilled life; it is also highly likely to cost the state more than provision of another TNF drug, although I appreciate that these are expensive.

I am devastated with the announcement. This announcement means that I may suffer many years of pain.

I liken RA to a virtual prison camp. Humira is the first drug, in the 10 years I have been incarcerated, to give me my freedom. The analogy to any action that would knowingly put me back there is clear.

I would like to express my disappointment at the decision by NICE not to approve the use of Orencia and to remove the right to move between existing treatments. This decision is the final straw in my attempt to keep my existing successful business going. I am now failing on my existing treatment and do not have the confidence that new treatments will be provided for me so have decided regretably to retire on health grounds and make my staff redundant. What a waste.

NICE must reconsider its flawed finding immediately

In 2001 I started Infliximab and from 2004 Etanercept and this is now giving signs of diminishing, and am deeply concerned that my quality of life will be impaired if this proposal goes through.

I feel this is a backward step in the treatment of a very dibiltating illness and by limiting the ability to try different anti tnf drugs it will leave people in a very distressing and upsetting situation and untimately put more strain on the health service to look after these people, where as trying a different teatment may allow them to lead a "normal" Life.

I was started on Remicade which was the best thing ever for me but when they started putting it in faster it upset me and therefore I had a bad reaction to it my consultant at the time took me off it and put me on Humira which sorted my pain levels out but upset an existing heart condition I was therefore transferred at my request back to Remicade and having it put in slowly and once more it is really helping me out again. Nice are not taking the whole picture into view the reaction to a drug is not purely based on your main condition other factors can make you react and therefore they could stop people getting a drug right for them with this silly ruling of theirs.

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Etanercept has completely changed my life. I am unable to take any other drugs for my severe rheumatoid arthritis, except for steroids, and the amount I had to take was having unacceptable side effects. I would be devastated if I couldn't switch to another anti TNF- therapy, if Etanercept ceased to work.

I can scarcely believe that NICE is taking this step to limit the treatment available to RA sufferers, and deprive us of the hope of possible relief from what is a debilitating and painful disease.

The NICE decision is short sited. Money spent now on TNF drugs would save spending in the future on joint replacements and sickness and disabilty benefits plus loss of taxes because people can't work. It would also save some people having to suffer great pain!

I am appalled that this backward step should even be considered, Etanercept gave me my life back - I have a full time job, exercise regularly don't need any financial help or make visits to the GP, I think sequential use of these drug is a must so that as many people as possible can live a full as life as possible.

Just another example of Gordon Browns influence by which money proves more important to him than peoples lives!!!!!

I feel, that if the sequential use of anti-TNF is withdrawn then many people, including myself, will be denied the on-going benefits of this drug therapy, because after a period of use, of any drug, the benefits reduce and as anti-TNF is given when all other medication has failed. Therefore, many people will be condemned to a life of pain and increasing immobility and damaged joints.

This proposal is clearly an appalling idea, with (it would appear) little logic behind it.

I cannot believe that people could be denied available treament and this could adversely affect me as Humira may no longer be suitable for me after 6 months' use.

I am hugely disappointed to hear this news of this NICE decision. Relative to many other diseases, RA gets relatively little profile or funding and, due to the complexities of the disease, the treatment breakthroughs are few and far between. Therefore, when they are made, however small, the positive impact it can have on sufferers and their carers and families can be enormous. Limiting the possibilities to improve the lives of the many people affected by this long-term, debilitating disease feels grossly unfair.

The suggestion that any form of treatment that can make life easier for a RA sufferer be with-held is a travesty, perhaps the NICE committee would like to spend a week in the body of an RA sufferer before and after treatment.

I am exhausted bythis illness and totally fed up of always being thwarted by NICE when there is some hope of a drug giving some relief to the day to day pain

"If NICE confirm this, RA sufferers will become third class NHS patients, compared to cancer patients for whom no effort or cost is spared to improve their quality of life; which I have full knowledge of as my wife is undergoing chemotheraphy at present following breast cancer operations last year."

I am extremely concerned about this development as I have no idea what treatment would be available for me if I have to come off Infliximab as I have been tried on all other treatments prior to Infliximab.

Having suffered pain and discomfort over many years and a myriad of various treatments, in truth none have worked and an alternative would give me what

little hope I have left for an easier life.

I was taking Humira which has given me a much improved quality of life but developed sensitivity to the drug so have switched to Enbrel - does NICE think that just because of an adverse reaction I should be denied the improved quality of life I feel I am entitled to? NICE - I don't think so!

Why are people with RA being treated like second-class citizens - would this happen if a first line cancer drug failed?

"So at 40, with one anti-tnf drug already showing signs of becoming less effective, my choice to lead an active life and keep working in the future is looking bleak......send me to the scrap heap NICE!

Please listen to the specialists! Provide and allow the correct medication available to help all with RA.

It is devestating enough to have RA, but it is unbelievably depressing (and unfair) that people in England and Wales (not Scotland!) should be denied the choice of treatments we so desperately need.

Life only ever seems as good as my rheumatoid arthritis is effective and the opportunity to move from one drug as its powers wane to a new one is a reassuring source of hope and of motivation to persevere when the pain gets very bad.

Limiting the options makes it more likely that I will need to lean on anti-depressants to get me through, and it seems crazy to be treating (avoidable) depression that would disappear if I had more effective treatment options to call on.

This is such disappointing to news to thousands of RA sufferers acorss the country. I have recently come of methotrexate for family planning, though will be looking to go back onto that or anti-tnfs in the near future. At the age of 30 i need to know that all of these options will remain open, as i will be living with this for many years to come - this is a terrible illness for those that suffer.

Despicable, how can the cost of a drug be measured against the pain & suffering that RA brings?

This announcement would mean living with the very real fear of severe pain returning if a current medication starts to fail, it is another pressure on an already vulnerable patient.

It is in the interests of our society to enable people to work and provide for themselves, the NICE ruling will remove this ability from a lot of people and it seems that the short term costs of the treatment have not been considered in comparison with the overall social and financial costs and will potentially restrict the lives of many RA sufferers to be constrained by pain, disability and poverty.

"If I had been unable to change treatments I would be unable to work thereby costing the Government disability benefit - do NICE want to make people unemployable living a life of complete misery with a disease which unfortunately does not seem to obtain as much high profile publicity/research/funding as other diseases."

Anti TNF is my only hope of a resonable quality of life, without it I could be sentenced to a life of pain and torture.

This announcement by NICE could mean the end of a useful working/family/home life for me full stop.

As an RA sufferer for 15 years, I feel very strongly that a patient needs to have 'hope' and a measure of ownership in one's welfare in order to cope- neither of these is probable if proven drugs are withdrawn for seemingly obscure reasons.

I have always been lucky that as one drug stopped being effective another came along to replace it. I am on Enbrel and if it stops being effective and I could not have another to replace it, it would set my R.A back to how it was years ago and I really dont want to think about that!!!!!!

i feel that this is totally unaccetable. as a ra sufferer holding down a full time job as a nurse and a busy family i think every thing should be made available to allow individuals the best oppurnity to lead a full and rewarding life.

I think it is absolutely disgraceful that people with such a painful and debilitating condition as rheumatoid arthritis are to be denied the drugs that have been proved to alleviate that condition.

The announcements are cruel and unfeeling - surely a purely financial decision - and I am only glad that I live in Scotland. I have had sequentially all the Anti TNFs and now have abatasept. In England I would presumably be expected to suffer my severe condition on nothing.

I am appalled by this announcement from NICE - my life has been completely transformed by Remicade which I have been on for over 8 years, always, at the back of my mind, is the thought that there is another drug I can have should it be neccessary - this could make me completely wheelchair bound again.

I find it very difficult as a relatively new sufferer, having been diagnosed some 9 months ago and for whom the normal medication has not worked, to contain my anger as well as being depressed by the continuing negative attitude of NICE to approving for general use the more expensive drugs. Whatever cost benefit model they use it would seem to be weighted to give them the answer they require and take little or no recognition of the deterioration of the sufferers condition and the effect this will have on the support required by the sufferer from the NHS and those on-going costs over many years in to the future.

I am horrified to learn that NICE are restricting the options on anti-TNF treatmemts,as an RA sufferer at present wating for the wound from an ankle replacement, 12 months ago, to heal before being considered for anti-TNF treatment, it now looks as if my options will be severely limited if I do not respond well to whichever anti-TNF is selected for me.

Thankyou for the information re the recent announcement on anti- TNF,I at present am not on such drugs but expect to be in the near future and am very dismayed at the governments decision both for all the people who are much more advance with RA than me and for myself for the future please lobby forcefully on all our behalfs

This is ridiculous, by cutting back options that have come with the advancement of science it will cost the individual as well as the economy as a whole in more people unable to work and more joint replacements when the arthritis is no longer controllable.

Although I have been prescribed Methotrexate for my rheumatoid arthritis, I can see that limiting the choice of medication for our condition is going to leave more people with no access to pain relief for their condition. This will also mean that they will eventually become disfigured by their arthritis. What are we supposed to do if they refuse us the medication that we need to maintain our quality of life? What a drain we would all be on the NHS if they continue with this attitude.

I'd like the people at Nice, who have made this announcement, to try and imagine a life where every day is a challenge both physically & emotionally, one where you have to pace yourself through each day with differing pain levels and ability to carry out your daily needs, and where not just your life is impacted, but the lives of your family, partner & kids, whom you have to depend on more and more to do the things you once could, but no longer can always manage.

I am absolutely disgusted with Nice's proposal with regard to the anti TNF drugs. Once again despite millions of pounds going into the NHS it appears that the level of treatment for RA sufferers is being reduced. Would the same recommendation have been forthcoming if it had been for heart or cancer care?

i think this is a disgrace, if these drugs help then they should be used at once on sutable candidates .i wish i could get this as my reumatoyd is bad and getting worse .

I think this judgement is a disgrace. I have just stopped one treatment, due to a reaction and will be trying another soon but if i hadn't of had a reaction then i would be in alot of pain with no hope of getting better.

My first reaction on hearing the latest announcement from NICE was anger followed by a dread of a future of unrelenting pain, immobility and a possible major dependency on my husband

For those of us who have tried endless medicines to find some degree of pain relief and 'life' this is like a nail in our coffin....what do we do if the medication we are on stops working ....give up!!!!!!?????? Who acvtually thinks of these protocols....do they know what R>A actually is? Perhaps they would like to live a day as an RA sufferer they would some review their idea!!!

I think that the people at NICE should suffer from the disease before saying that people with RA should not be allowed to go onto another TNF medication if the one they are on ceases working.

I was astonished and disappointed at the rulings by NICE not to allow new anti-TNF abatacept (Orencia) to be prescribed and especially to no longer allow other anti-TNF drugs, already licensed and approved by NICE to not be given sequentially; this is so short-sighted of NICE as the NHS will be picking up the bill for years when they have to treat all these patients as their conditions worsen and will cost them so much more in the end.

How can an organisation such as NICE decide what drugs an individual can have access to when everybody reacts differently to the disease AND the treatments available?

"You try your very best to live and work with a condition which can be very painful and debilitating only to be delt another blow by a body who you would think would be helping medical causes it's like being threatened with a death sentence (FOR SOME SOONER RATHER THAN LATER)". It's a pity it all comes down to cost.

The use of the three anti-TNF therapies, Enbrel (etanercept) Remicade (infliximab) and Humira)adalimumab, will by their very nature have a varied results. If the user has not found improvement of each and everyone of the three, then surely to me it would be unethical not to be given something that may help.

I believe the value of such drugs, in my case Enbrel, has given me my life back. The journey to the year 2005 was the classic painful damaging trip. My life now is, my life I, although a wheelchair user is, pain free. I am enjoying a quality of life that I can rejoice simply in one word, "whoopee"

I sincerely hope one or more NICE members quickly become R/A sufferers which may persuade them to change their wholly erroneous and totally misconceived recent decisions that will have such devastating consquences for others.

The withdrawl of the sequential use of Anti TNF treatments is a disgrace which should lead the commitee who made this decision to hang their heads in shame, this action will lead to patients in England and Wales being condemed to living a life of agonising pain.

"Rightly or wrongly, the public perception of many of NICE's decisions is that they are based on budgetary issues rather than clinical considerations - I would therefore like to ask NICE's accountants - how do you put a monetary value on the control of pain?".

As a young person who has so far benefitted greatly from using anti-TNF medication I feel extremely disappointed by the news that sequential treatment may be stopped. To have this further hope for a good life taken away is very upsetting.

I would like to say this is very worying i have rheumatoid arthritis and at the moment it is controlled by methertrexate & diclofenac which i have been taking for about 4years after the treatment i was on no longer controlled it. im woried about what will happen next.

My name is [redacted] and I live in [redacted], [redacted]. I am 53 years old and in recent years have become severely affected by rheumatoid arthritis, I now have to use a wheelchair for even the shortest of trips out, ie to visit my GP, Consultant etc.
I am about to embark on the road of anti-tnf treatment and have opted to use Embrel. My first injection is scheduled for Monday 12th May.
I am extremely disappointed to read the announcements by NICE. I felt really encouraged that I have been given the opportunity to use these drugs and feel that two thirds of the carrot has not been snatched away.
Like most sufferers I feel that my Life has been taken from me since the rapid onset of this crippling disease. My Life is not how I imagined it would be and after 25 years of fostering severely disabled children I was looking forward of spending time with my Husband, which I did not foresee would mean him helping me on and off the toilet!, and also of spending time with my Grandchildren, if only one of the people who make these decisions had to walk in my shoes for 24 hours, or in the shoes of my Husband whose primary role is now as my carer and not as my partner!, I am certain their decision would be different!

Anyone who can consider recommending this 'shutting of doors' action has, quite obviously, not experienced or witnessed the agony, despair, exhaustion, hopelessness and helplessness of this disease.

I am contacting you about the decision not to allow sufferers to change if the Anti-TNF ceases to work, in my case it will put me back 14 years by the only treatment I will have will be GP issued pain relief, so I am asking to have this dropped

As I feel Atanacept is losing it's efficacy for me, and I am about to experience my second and shortly third major joint replacement operation since being on the drug, this announcement is potentially devastating for me and could could have a seriously detrimental affect on my future quality of life.

This is outrageous ! do they really want people to suffer

I have been on Enbrel for over 5 years would hate to think that if this drug became ineffective over time that an alternative would not be available, as it has had such a positive effect on my life.

I am extremely disappointed to hear of the decision by NICE (not quite the appropriate name!) to ration Anti TNF treatment. It has taken several trials of different drug combinations to control my own Rheumatoid Arthritis. The successful treatment justifies whatever the cost.

I strongly disagree with the decision by NICE and feel that those of us unfortunate enough to suffer from this disease should have all possible options for treatment with the extra costs being sourced from less serious conditions.

Just dreadful!!
When you take away hope - you take away everything

I have just started on Humira after my consultant told me he didn't believe we had ever really gotten control of my RA, my reponse so far is better than I could have hoped for, I am really grateful for the opportunity to use this drug and hope others have the same chance. There is no pain like RA, anything that can improve this situation must be welcomed.

If, after taking Humira for the last two years, I returned to the pre-Humira condition and an alternative anti-tnf medication was denied, the pain and agony would make life not worth living.

Two years ago I was heading down the path of being unemployable,dependent on the state,needing help. By changin treatments my health improved and I am now regained musch of my health,life and have less pain and fewer flares. I cannot belive that anybody would or could refuse treatment that gives back independence and allows manymore years of better health which in the long run will be cheaper to the country

As someone who is benefitting from anti TNF, I am very disappointed and extremely worried about NICE's announcement re sequential use of anti TNF; I feel that a lot of people with RA may face unnecessary suffering and misery if they are denied a 2nd anti TNF.

This deeply saddens me, We need these drugs, it's not just a whim, without these things we are helpless, and yet the government wants us all to go back to work? I can tell no-one involved with NICE have family members with RA.

I have only recently been diaganosed with RA and can't believe the difference in my quality of life since taking methotrexate. However,who knows what the future holds for me and I might require different treatment. This announcement by NICE has reduced the options for me to try different treatments if one doesn't work and as I am only 46 I feel extremely concerned that if my illness deteriorates I could revert back to sleepless nights and continual agonizing pain throughout the day.

Limiting the ability to change to a different medication is not only cruel but ineffiicient in treating the disease that is RA- in its nature it is hard to treat and find the right treatment straight of- its appalling, my mother has severe RA and had tried a number of medications to no avail-what do NICE suggest, that she has had her lot and should be left to flounder- are we really living in a 2008 Britain? APPALLING!!!!

Yet another backward step in the care of those with rheumatoid arthritis. NICE appears to be in place to stop treatments and save money by doing so,but does nothing to benefit patients who have diseases such as rheumatoid arthritis. Unsurprising the way the health service is going, but sickening nevertheless. Amazing that they can pump money into services such as 'giving up smoking' by the millions (when people do after all have a choice as to whether they do that or not) but can deny important drugs to genuinely sick people! IT MAKES ME SICK.

This is a unprecedented retrograde step which will not only cause increase pain but will limit the mobility of those severely affected by RA.

At the moment I am watching RA taking control of my body, my life style beyond my recognition, I cant beleieve how depreesing the news from NICE is. Do we not deserve a chance to live a life that is nearly normal?

Thank you for the opportunity to reply. If my present treatment were to become less effective and no alternative biologic treatments were available to me, the outcome would be pretty devastating - I would go from being a relatively normal working person to a disabled individual who would then cost the state a great deal of money.

This is appalling, obviously nobody who works for NICE has Rheumatoid Arthritis otherwise they would know how important and life changing our drugs are!

I am shocked at the NICE decision not to allow a change from one anti TNF treatment to another. From personal experience I function well only because I was given a second anti-TNF drug when the first one, Humira, became less effective and was making me prone to chest infections.

Just another blow to all of us out here with Rheumatoid Arthritis !!

I would be interested to know how NICE justify the refusal of Orencia and sequential use of anti-TNF treatments. Do we assume that their organisation is made up of people fortunate enough to be completely healthy? If they had suffered the pain and indignity experienced by those with RA they would surely have a more sympathetic approach

all we can say is N.I.C.E .NUMBSKULLS.IMPERSONATING.CLINICAL.EXPERTS lets all ask for there name to be changed

i myself have been on three anti tnf drugs the first one having worked for a while (infliximab) then i had a severe allergic reaction. i then went onto another (humira) which worked great for about two years then suddenly stopped working. i am now on enbrel and have been for two years but now seems to be showing signs of failing yet again. i think its an absolute outrage that these people can mess around with peoples health if i had not had the chance to try other ant tnf treatments i would have had no quality of life. although they have not worked as well for me as other people they have still given me a better life. i wish these people could no what it was like to have RA then i am quite sure there attitude would change.

This announcement is an absolute travesty - the use of a 2nd anti-TNF treatment has given me, my husband, my daughter and the rest of my friends and family our life back - its not just about me but my whole network of friends and family enjoying my new found energy levels and mobility.

ANOTHER POSTCODE LOTTERY > DOES ANYBODY AT NICE SUFFER !!!!!!!!!!

It appears to be both cruel and illogical not to permit sequential use of anti-TNF treatment – if my current anti-TNF (etanercept) fails, I shall be in despair if I have to return to the levels of pain and inactivity of my pre anti-TNF days without the opportunity to try other versions of the treatment.

The NICE announcement is very disappointing as it is taking away the freedom every unique, individual RA patient needs to be able to switch from a medication that is proving ineffective to a medication that will be affective, and this freedom has meant the difference between an independent, productive quality of life versus a person dependent on others for help and care.

If these people knew what real pain was, they would not deny RA patients anything, stop meddling in things you know nothing about.

I am currently on my second anti-tnf therapy. Humira worked for 3 years then failed - I am now on Enbrel which I am pleased to say is working very well.

I am 34 years old and these drugs have given me my life back, I am able to work full-time, live alone and have a social life! They make the disease manageable and if (or more likely when) my current meds fail I will be out of options - I don't want my life to be over because my disease isn't seen as a priority. This decision by NICE disgusts me - these drugs could mean the difference between an independent life or one in care for many people. Ridiculous.

This is a thoughtless cruel decision by NICE and I am sure this is driven by money, anybody with this horrible painful disease deserves the choice of treatment to help them lead a reasonable life.

Based on my experience of RA before I received any drug treatment, I am now terrified that should my medication cease to be effective I could be written off, lose my independence and dignity, and die in chronic acute pain. Absolutely not "nice"!

After only 4 months on my 2nd. anti-TNF drug, (the first lost its efficacy after 3 years) I feel very well and have just returned from a walkng holiday in New Zealand - if this option had not been available I would now be struggling to cope with everyday living with very little to look forward to.

Get your wheel chairs serviced now we could be needing them more and more.

Finally getting access to Enbrel gave me my life back. I can work, pay taxes, care for my family, be a citizen. I live with the knowledge that it could stop being effective tomorrow, and NICE are now telling me and thousands of others with RA we only get the one chance, if that doesn't work: tough - it's wrong ethically, financially, morally.

Nice is once more denying people with severe RA the opportunity to lead a normal as possible life.

"Having just returned to work after 2 years thanks to anti-TNFs when every other drug that I tried had failed I am now hanging by a thread again because if this one drug stops helping me, I'll never be able to work again".

RA is crippling to your relationship, your career and your mental health and most obviously your body. Nobody who has experienced the disastrous effects of RA would ever allow an individual to suffer with this undignified disease. Giving specialists the drug therapy options that are known to be benefit those who's options are dwindling gives sufferers confidence that we are winning the battle and bring countless people the independence to work and live a fulfilling life.

I am a person with severe RA who has already tried the more usual drugs (methotrexate/Diclofenac/Sulphazalazine) but they caused necrosis of my liver. I am about to embark upon Anti-TNF treatment, (which is a very scary prospect) and am appalled to learn that NICE has made this decision ref sequential use of anti TNF drugs - this surely condemns me to only one hope and if Enbrel fails me I'm doomed..??!!

This is certainly alarming news that NICE is proposing.I would like to say to them"Sit in my chair,see how you feel when all hopeful drug treatment is withdrawn,hope is a marvellous thing it makes each day worthwhile.,without it life would become short."

"Again, NICE seems to be quite happy to condemn people to the scrapheap, perhaps they should be reminded of the Hypocratic oath because this backwards step will undoubtedly cause an unimaginable amount of pain (both physical and psychological) to a lot of people!"

I have severe rheumatoid arthritis and at times could not move any part of my body but thanks to these drugs I am in remission and am painfree at the moment - I NEED these drugs.

Having had a life changing experience when offered Embrel injections the following year it had been sanctioned and having tried all other remedies available at the time which either did not suit or had grown immune to a medications effects, I would be positively gutted if, in the event, Heaven forbid, that my system ever got immune to Embrel that I would not be offered another similar Anti-TNF treatment if not, I would be reduced to a near 'cripple' as I have the disease in my toes, ankles, knees, shoulders, wrists and fingers.

PLEASE LET IT HELP STOP THIS LUNACY!!!!!

without hope there is no life, and I was therefore devastated at the news that NICE has banned the use of Abatacept and the sequential use of anti-TNF treatment.

I'm devastated, & disappointed my life is difficult enough. Please dont make things more impossible.

I am disgusted and worried, anti-TNF drugs are a must for me to live with some normality, I could not cope now without it and would expect to be able to change if necessary. I am going to write to my MP because unless you actually suffer with RA you don't realise the importance of these drugs.

I feel abandoned with no hope or relief from excrutiating pain - not so NICE!!

Sequential use of anti-TNF drugs offers individual R.A. suffers an opportunity to reclaim participation in living. You do not even chance to predict that your mono-chrome existence could transform to a lush multi-sensual enjoyment for each day.

I am such a patient who failed on one anti-TNF drug and thankfully switched to another. Until it is possible to accurately predict which Anti-TNF treatment is appropriate and sustainable for

which patient, it is implausible to conceive that sequential use of anti-TNF could be withdrawn.
Humira made me very unwell, and I remained on it for six months while it was proved to be clinically unfeasible. I have been on Enbrel for one year, which after a few initial infections allows me to feel optimistic and confident for the first time in nearly seven years.

Is this not interfering with my Human Rights, it is bad enough suffering from Rheumatoid Arthritis, without some not so NICE boffins deciding my future.
☹

i know it is not a nice thing to wish on anyone, but the people at nice should try having severe r/a for a week,they would soon change their minds,yours ,alan ridley

This announcement neglects to take into account the reality of the pain that people face in their daily lives and takes away the hope that makes them endure their existence.

every time I have another operation and have to stop my anti-TNF drugs for a while, I'm reminded that without them I just wouldn't want to carry on, they are a gift of life, a temporary respite for the condemned.

NICE must reverse this decision on the restriction on further anti TNF drugs

Having had Rheumatoid Arthritis sinc the age of twenty, I am now 48, I would not be able to work full-time, were it not for the drugs that control this chronic, painful and disabling condition. Would it make sense if I were denied the drugs needed and end up not being able to work and rely on State Benefits?

Having had RA for nearly 4 years, at present successfully treated with Methotrexate, it is horrifying & worrying to hear that future possible treatments are now limited.

The decision by NICE this week will deny me a chance of a third anti-TNF therapy if I need it
Many patients with RA which is a life long illness will all be affected by this mean decision to ban sequential use of anti-TNFs

It is absolutley ridiculous to be declined any further treatment with a different drug just because another does not agree with you. It is like saying we will only have one cough linctus available for everybody even though this one may not agree with everyone and there are another 50 linctus on offer. But never mind eh its just RA.

As a patient who has taken her second anti TNF drug with a huge success I would say what NICE plans is outrageous.

I am horrified by this potential decision, I regained my life with Humira and if I had to lose it and go back to how I was I would with no other alternative I would seriously consider ending my life - that is how bad I was and I do not want to revisit that ever again.

I am not on any anti-TNF treatment yet but should I ever need it, it feels like one of our life lines has been cut with no alternative AT ALL.

I have had RA since I was 34 and in the 23 years since diagnosed I have striven to keep as positive, active and independent as possible, with the help of any drugs prescribed by my consultant and I feel that the success of the the anti TNF treatment means, that it is essential to allow the sequential use of anti TNF in order to keep people like myself able to lead as normal a life as possible.

Having benefitted from a change of medication in the past, the decision of Nice to limit the options for future changes is depressing and worrying.

Implementation of the NICE ACD proposal will condemn may RA sufferers to a life of suffering and unnecessary discomfort, for short term monetary gain by not looking at the full picture.

If anyone on the NICE panel could experience the relentless pain and disability of Rheumatoid Arthirits they would realise this decision is cruel and is not cost effective.

Humira has allowed me to be a proper mother to my young children; without it, or a sequential alternative should it become less effective, it would not only reduce my ability to care properly for my children, it would also significantly reduce the quality of life of my whole family who depend on me both emotionally and financially.

I feel nothing but despair each time NICE denies treatment to sufferers of inflammatory arthritis, and the decision to refuse sequential anti-TNF therapy makes no sense at all.

This announcement means that if I choose the wrong anti TNF as I am shortly starting treatment then any chance that a change of drug might offer a further chance is gone and the government can look forward to paying tens of thousands of pounds for my care as me and my partner grow older because we are now in our early sixties and the situation will grow steadily worse how stupid is that!

I have only suffered from RA for 18 months, currently I do not need anti-TNF but may do in the future; I am fortunate to have a job where I am able to take a short nap in the afternoon thus I am able to continue contributing to society, without this facility, I would have to give up work: NICE appears to be working in opposition to government policy regarding disabled people - do I just fade away and drop off the radar?

Thank you for keeping us informed about these latest NICE deliberations.
I was really dismayed to hear that we could now be restricted to just one chance on ANT-TNF therapy.

I have suffered from RA for the last 6 years & am really struggling to keep in employment in my teaching career, due to pain & disability, as well as general day to day living.

Last year, whilst waiting for anti-TNF approval from my PCT, I had great difficulty battling on with Diclofenic as my sole medication for over 6 months, having had unacceptable side-effects with DMARDs .

I am now having some improved relief with Enbrel & prednisolone & I am very grateful for this, but for how long?
The thought that this could be it, & there will be no further alternative anti-tnfs funded, should I need them, fills me with dread for the future, both for my career and my self care and quality of life.

I do so hope NICE will be able to reconsider their recommendations.

Whilst not requiring this drug at the present time I feel that this option should be kept open as it seems to be giving people quality of life which they will not have if this drug is taken from them and for such a small amount of money. In the long run I am sure the cost would be much greater as the people would need more and more appointments with their Consultants as they will be experiencing all the same old health problems.

What is also very upsetting is the financial investment for research to develop these drugs only for them to be denied for a relatively small increase in cost in comparison to other drugs. What price are they putting on someone’s quality of life.

Regarding the announcement by Nice recommending that people in England and Wales will no longer be allowed to change to another anti-TNF drug if their original one stops having any effect. I was prescribed etanercept about four months ago when the standard drugs I was given for four years were not having much effect. I cannot emphasise enough how much difference this has made to my quality of life and vast reduction in pain from which I was having. The thought of not being able to try another anti-TNF if the effect of this drug gradually diminishes fills me with dread, I am just beginning to live again, I DO NOT want to go back to those dark days ever again!!

"With the knowledge that medication is available to give me a better quality of life, it would seem like a very harsh decision to acknowledge that this opportunity of having a 'normal' pain-free life was being denied."

Rheumatoid Arthritis is an extremely debilitating and painful condition and can effectively cease the sufferers' ability to perform everyday tasks and therefore be a useful member of society; these drugs to a large extent reverse this situation and allows the sufferer back into the workplace/society and therefore not be a burden.

When I was first diagnosed with RA I felt my life was over as I was unable to perform many everyday ordinary tasks. Doctors are still trying to get the right medication for me and to deny the use of the different drugs that are available is like adding insult to injury. We have finally got the ability to make life more bearable for people who have RA only to threaten its removal.

I do not feel it is in anyones best interest to deny access to drugs which may help to keep people
from becomming a disability statistic.

After trying a number of different drugs to try and control my rheumatoid arhtritis over a number of years - all of which had no effect (apart from side effects), the last one landed me in hospital as it was damaging my liver. I was then allowed to try an anti-tnf drug, and I am now on etanercept which has transformed my life At last I have very little pain and it is allowing me to continue working. The recent two annoncements mean that if the etanercept stops controlling my RA then there are no other options open to me. The thought that I could go back to an uncontrolled, rampaging and very painful RA is, quite frankly, frightening. This decision must be reviewed.
PS I have also sent an email to my local MP Janet Dean

I think this is an absolute disgrace. These drugs enable me to function and witholding this treatment is condemning RA suffers to a life of pain, disability and deformity.

In complete contrast to its own definition of being "..responsible for national guidance on promoting good health and preventing and treating ill health...", NICE is demonstrating its capacity for denying sufferers the chance of being treated and of having their health status improved - I am living proof that my current anti-TNF drug, rather than the previous, is highly effective for me, allowing me to remain fully employed, contributing tax and NIC to the State as opposed to being a burden on it, which I might indeed become if I am denied any change that might become necessary"

Thanks for the above email. I was however greatly concerned by it's contents as I am at present on my 2nd anti TNF a treatment which is working well and has been for the past 2 years. I will now have to keep my fingers xed.
My response to NICE is difficult in one sentence, however here goes
Sentence is what RA is, a life sentence, and Anti TNF's give back some quality to that life, to refuse this option is criminal and unjust, I am very angry, horrified and also terrified of what my future now holds.

this would be very serious for myself as the enbrel anti tnf treatment i am on at present and responding well to may be withdrawn if my symptoms got worse and i wouldn't be offered another alternative anti tnf.at present i have returned to work after 2 years on the sick with severe r/a.if my symptoms returned and enbrel was withdrawn and i wasn't offered an alternative i would not only be in severe pain and unable to work my quality of life would be awful again.

Yet another let down for people with RA. Obviously we are second class citizens. Whilst this does not affect me has I do not take TNF drugs my thoughts are with those that desperately need them. Surely by giving these drugs to those that needs them is more cost effective as in the long term without the help of these drugs sufferers will cost the state more in social care and state benefits.

Having Severe RA for six years, honestly, life would not be worth living if I had to continue to live with such pain. I am now on a good combination of injected methetrexate and Gold. ! I would like to know what valid reason (NICE) have given to reject the new clinically proven drug. We need as many options as possible.