

Annex 2 - Restoring Hope?

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Bernadette started by challenging our convention title. Indeed, the definition of hope is often a mixture of passivity and simplistic optimism, such as the Wikipedia (French language site) defining it as "A disposition of the human spirit that consists in waiting for a good or better future". If restoring hope would just be waiting for the best to happen, it would be very close to denial or refusing to see a reality that would be unbearable. This is something we regularly see when people with lupus say that they are doing very well and refuse to take their treatment while their proteinuria scores are climbing dangerously. When hope is excessive, resulting in an unrealistic approach to the facts, it can obviously be negative. Restoring Hope is certainly not that!!!

Rather, Bernadette recommends defining hope as positive psychology (not positive thinking, like the Coué method) does, linking it with action in an inseparable manner. In the face of uncertainty, positive psychology assumes that there will be a favourable outcome and will push for action to facilitate this positive outcome. Hope is then a way of thinking but also a way to advance. Hope is the conviction that solutions are possible and that we are able to act. Hope is to think that every person, including ourselves, have an extraordinary potential for inner transformation and action. In front of the uncertainty of lupus, I will accept the situation, and then I will try to look at it in an active way, giving myself the right to consider a positive development to events and to act in that direction.

So, it is not necessary to spoil your life by rehashing the problems, but rather you can brighten it up by searching for positive sides or ways to improve things, taking responsibility for what we can change.

It is essential to have a fair balance between optimism and realism. Aaron Timothy Beck says that good mood is two-thirds positive thoughts for a third of negative... 66/33, that is slight optimism. Our negative thoughts are necessary because they protect us and allow us to remain realistic. Some use the term "Intelligent optimism", which derives its strength from the ability to imagine a favourable outcome to events and to give them more positive than negative reasons, but at the same time remaining lucid on the reality and the efforts to be provided.

Bernadette then explored the "objective" reasons that people with lupus often lose optimism, explaining that depression is substantially higher in people with lupus than the general population:

1. Symptoms of lupus are presented in a general way suggesting they are permanent: "90 to 95% of people with lupus suffer from muscles- or joint pain" permanently associates lupus and pain, rather than to clarify that pain outside of flare is, by definition, not lupus driven. This creates a nocebo effect: the very idea that one should have pain is a formidable mean to actually have pain!
2. Doctors (have to) insist on side effects of the treatments, and as a result, drugs are associated with their side effects rather than their benefits: Plaquenil means Retinopathy rather than reduction of flare and increase of survival. Cortisone is associated with Osteoporosis rather than "cut the symptoms". The patient then becomes sometimes more afraid of the treatment than of his illness.
3. Patients who are doing well do not speak on the internet, where negative rumours proliferate, increasing patient anxiety and slowly but surely putting them in despair.
4. The unpredictable side of lupus is presented as a fatality, leaving the patient powerless. In labs, rats with cancer, receiving electric shocks see their cancer evolve slower when they have a possibility to act (by pushing a button avoiding electric shocks) than those that cannot... The feeling of powerlessness is a driver of anxiety and despair. Nevertheless, the reality is that we are not powerless against lupus: just by adhering to treatment, we substantially reduce the risk of flares since not taking the treatment is today the largest single cause for flares!

Optimists live longer and healthier as demonstrated by countless studies. Thierry Janssen, a Belgian surgeon turned psychotherapist even claimed that "an optimistic attitude towards life is the most powerful and least costly drug that human beings have ever had at their disposal". Some of the effects of optimism are visible in biologic parameters (blood glucose, lipid profile), some in behaviours that have an impact on life expectancy (less smoking, ...) but those factors are not sufficient to explain why optimists live longer and healthier... Yet, Bernadette reminds us that we must not fall into the illusion that one can tame lupus just by our optimism and "inner forces", and that those failing have not been able to dominate lupus sufficiently! Not only is that ridiculous, but also adding guilt to the burden of disease, is not only counterproductive, but above all appallingly unfair.

So, the question is how to restore hope? There is no magic wand that works in every situation, no easy trick that can be taught in 15 minutes, but some things should better be avoided, and others better done...

There are three different "targets" to restoring hope: other individuals, ourselves and lupus groups.

Restoring an individual's hope:

Bernadette advised us to first listen to the person, with respect, empathy and authenticity.

Respect: No fear is stupid. It is important that people understand that you have respect for their beliefs and fears. This does not mean "approval", but listening with kindness, without interrupting, giving them time to express their secrets fears... Understanding their concerns is the first step to restoring hope!

Empathy, which means being at their side and trying to see the facts as they see them. Reformulating what they say, not just saying "I understand", but rather "if I understand, the worst thing for you is the wheelchair". Putting a clear name on things is important!

Authenticity: if you are not able to be fully present and authentic with the person, don't try to restore hope! You must believe in what you say, sentiments or facts. Or it will sound fake, and you will fail in restoring hope.

After the time to listen, it is important to bring clear facts and figures about lupus. Most of the time, people believe that their lupus is worse than it is in reality! It is also important to remind people that statistics can be misleading: The fact that 30 to 50% of people with lupus stop their professional occupation is very scary, but each person has a different risk for that, depending on the type of job, the education level, the severity of the disease, its duration, ...

There is no point in denying concerns with overly optimistic statements like "Don't be afraid, all will be soon OK." If believed, this encourages non-adherence to treatment ("Anyway, everything will be fine in the end") and brings huge disillusion later on. Rather, be realistic and express that lupus will bring difficulties, time wasted in medical follow ups, lots of medicines, but at the same time say that the likelihood is very high that he or she will be able to adapt and continue with a good life.

Restoring hope for people with lupus is to promote an "intelligent optimism", both an engine for driving projects and realism on the difficulties to overcome. When you repeat to patients that they have the means to live well with the disease and to succeed in their lives, you give them faith in themselves and in the future.

A big watch out is that some people are in such a mental condition that they simply cannot hope. This is unrelated to the severity of their disease. Even with a very mild lupus, some people are convinced that they will die in a couple of weeks. And sometimes, no logical or exact information, no support, will help them. You then need to accept that this is beyond what you can do, possibly advise them to get external help. We are not all-mighty and capable of 'restoring hope' to everyone. It is also important to protect ourselves by putting a limit on the time we dedicate to the "chronically desperate people" to avoid reaching the limit of our patience and throwing them away in an inappropriate way!

Building our own intelligent optimism:

To be authentic, we must first "Restore our own hope" and be in a mindset dominated by "intelligent optimism" ourselves.

Just as we can ruin our health and life by rehashing our problems, we can strengthen it by looking for happy emotions. We have a rich potential that we must learn to use and develop by fighting against our tendency to self-deprecation, anxiety and pessimism. And this can be learned via methodically training. It is a journey to detect our own sources of satisfaction, grow them and build the life that fits us. It is important that we truly believe that there is a solution, even imperfect, to any problem. We have not chosen to have lupus, but we can choose our way of living with lupus and to look at lupus in another way, focusing on our possibilities, not on our limitations, becoming directors of what happens, not victims.

Bernadette suggests as an example of personal development exercises to wake up 30 minutes earlier, taking ownership for our day rather than being subjected to it. As you wake up, take the time to enjoy the silence, to consider yourself positively, to remind yourself of the "little victories" you can be proud of. Saying positive things about yourself on a regular basis increases your faith in the future. Then, consider the day ahead with a focus on pleasant moments, tasting in advance the feelings that will animate us at that time. The next moments should be dedicated to stretching exercises or yoga, to breathe calmly, to meditate, read a few pages of a good book, write in a diary, go jogging... The goal is to start the day with things that makes you feel good, but that you never take the time to do. Of course, it means you have to go to bed half an hour earlier the evening before, but it's worth it!

Another suggestion to build our intelligent optimism is the "visualization technique" to counter negative events: Visualize the worst possible outcome in a detailed way, and with a maximum of emotions, frame mentally the scene with a small dark blue frame and shout "I don't want that". Erase it and re-visualize in a positive way, with a large white frame and say "I want it to happen like this"; it helps to record our desires in a positive way deep inside ourselves and dispel anxiety. Even if things still go wrong (it is not magical!) the impact of this failure will be less.

Other suggestions from Bernadette:

- The "as X" game, thinking at how a person who represents optimism for you would react, and seeking to adopt the same attitudes (smile, right posture, straight shoulders, calm breathing....). If the psychological influences the physiological, the opposite is true also!
- Setting Smart (Specific, Measurable, Action Oriented, Realistic, Time Bound) goals to yourself. Every goal achieved, small or large, increases your self-confidence, personal esteem, and positive approach.
- Improving your physical condition (exercising regularly).
- Surrounding yourself daily with little things that give you a smile: photos, music, plants... meeting optimistic people and not people who pull you down. Optimism is contagious! Have fun: go out, laugh. Evacuate regrets and remorse.
- Expressing gratitude and joy, being more altruistic and generous: giving without expecting anything in return makes you happy.

Building hope in your lupus group:

We cannot distribute hope like cookies, but we can create an environment that helps people cultivate hope. One of the ways to do this is to follow Timothy Beck's rule 2/3rd positive for 1/3rd negative. Ensure that your group's publications respects at least that proportion, creating the base for people to have hope.

Formally advise patients to consult only moderated groups if they want to interact on the internet. Faced with an adverse event, optimists will find an explanation limited to the event in question, pessimists will generalize: "everything goes wrong, everything will always go wrong, with me, everything can only go wrong... ". So, people in need for hope will easily consider that the worst things that they read on internet

will happen to them... One person dies of lupus, everybody panics. So, avoid connecting to anxiety generating groups!

Publish positive stories of people that have lupus, even very severe, but keep a positive attitude, like the "Reporters of Hope" award that highlights what is going well in the world, it is important to highlight these stories of patients who have managed to live in peace with the disease.

Ensure intelligent optimists moderate your lupus meetings.

Offer one to one time for people to express their negative feelings so that they do not pour it at length into a large group.

Provide complete and solid facts, easy to understand, and ideas for action for people to "beat the probabilities".

Remind people that non-adherence to treatment remains the number one cause for flares.

In closing, Bernadette urges us to find our own solutions to building hope, and to share them across countries so that the best ideas can be replicated across Europe.