When illness puts work into a different perspective

Life expectancy is rising, as is the duration of working life, while new treatments are helping people work longer despite being ill. But there are still very few support schemes for helping people to get back to work or change their field of work. “Chronic illness and activity” support groups were an experiment, focusing on peer-to-peer exchanges and getting people out of their isolation.

Elsa Fayner
Freelance journalist

“Being part of this support group helps us to realise that we are not alone in these situations.”
Image: © Martine Zunini
“I didn’t feel well, I didn’t know to get out of the rut, how to get myself back on track.” Now 65 years old, Nadine was diagnosed as having breast cancer in 2010. At the same time, the training centre she was in charge of—a centre for people in difficulties—had filed for bankruptcy. Nadine’s primary focus was initially on closing down the centre, while also starting the treatment. But once the administrative steps had been finished, her cancer started showing its ugly face and Nadine felt “very, very bad”: “I wasn’t old enough for retirement. I had cancer, had filed for bankruptcy, was out of form... I went from having lots of responsibilities and energy to having nothing at all, because I just wasn’t able to do anything.”

48-year-old Isabelle* from Paris went through the same: “After having been off work for three months following the cancer diagnosis, I was able to go back, though only part-time. I found this to be the only way to cope with the fatigue and pain, while at the same time making some money and feeling of use to the company I worked for. But it put an abrupt stop to my career.”

Though her illness has since stabilised, she is no longer happy with her work, feeling that she has been “relegated” in her department, “blocked”. “I’m being given less interesting things to do. It’s not easy to keep hold of stimulating cases when you’re not there all of the time. Not working full-time is still not the accepted thing in France.” It was the doctor who had suggested to her to work part-time on health grounds. At the hospital, Isabelle also had a session with a psychologist on being informed of her diagnosis. “But that was just one-off support. I couldn’t really find anybody to speak with about working while ill”, she regretted. But what helped both Nadine and Isabelle was a flyer informing them of the existence of a club specifically for people like them, the “Club maladies chroniques et activité”. Located in the Cité des Métiers in Paris, the club offers people suffering from chronic illnesses, first and foremost cancer, support for a limited time in getting back to work.

**Older workers, more likely to be ill**

Italians take retirement at 65, Belgians and Germans at 67 (as of 2029-2030) and Britons born after 1970 at 68. Sweden has announced that it will be raising the official retirement age from 61 to 64. As a result, Swedes will be able to work until 69, against 67 at present. Throughout nearly all the European Union, men and women are going to have to work longer, well into their sixties. Yet, for the majority of cancers, the risk increases with age. Many forms of cancer rarely occur before the age of 50. According to the Belgian Foundation against Cancer, on average, 60% of cancer patients are older than 65. According to a large-scale survey conducted in France in 2016 by the French Institute for Public Health Surveillance (InVS) and the National Cancer Institute (INCa), the 5-year survival rate has improved over the last few years for the main forms of cancer. This basically means that more and more Europeans are likely to be ill while still working, creating completely new situations.

Cancer is one of the chronic diseases defined by the World Health Organization (WHO) as a “health problem requiring several years of care and often involving invalidity and the threat of serious complications”. While covering very diverse realities, these diseases have two things in common: their duration which no longer allows them then to be seen as a brief interlude in the course of a lifetime, and an obligation to manage the chronicity in all spheres of social life. For those suffering from cancer, treatment is not a synonym for cure but for coping. Chronic diseases differ from acute diseases in their duration, their alternating critical and stable phases, and the unpredictability of their evolution. Apart from phases of intensive treatment, they do not necessarily mean that paid work has to be suspended. Nevertheless, they do constitute a higher risk of occupational disability, of work limitations, of job loss or a change of job, of absences from work. Little visible or even unutterable in many cases, the consequences of chronic disease are often underestimated, denied or not properly understood, and hardly at all debated in the world of work. However, as shown by several qualitative studies of sufferers of working age, the majority of them want to continue working or to return to work, not just on financial grounds or for the interesting work and the contact with colleagues, but also because work is a powerful instrument for escaping from the grip of the disease itself and from the imprisoning social status of being ill. How are these alternating treatment/work periods experienced? Is returning to work promoted or not? What support schemes are available? What can be learned from the “Club” referred to Nadine and Isabelle?

**Very few schemes**

After having filed for the bankruptcy of her training centre, Nadine registered with the Job Centre and, with the encouragement of her employment counsellor, requested a skills assessment. “Apart from the Job Centre quickly directing me to a service provider for the follow-up, and apart from the latter – at 1:30 on the bus from home – requesting me to do an internship and to write to as many employers as possible, there was no support at all”, remembered Nadine. “The requested skills assessment was swept under the carpet, God knows for what reason.” At that time, the 60-year-old felt too weak for a full-time internship and a fast-track return to work. She had no idea whom to contact, who could support her in finding new work while taking the time needed to look after herself and rest. It was the same story with Isabelle, whose company was similarly little able to cope with the situation. Her annual appraisal sessions did not lead to any improvements, despite her repeated requests. Since informing her company of her illness, Isabelle, who worked in marketing, had been entitled to no more than two days of training.

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1. Forenames with an asterisk have been changed at the request of those concerned.

"Peers don’t judge. They also don’t take pity on you, in contrast to certain friends who give advice."
However, in France, a number of companies have signed the Cancer and Employment charters drafted by the INCAs, undertaking “to retain staff suffering from the disease and to help them return to work”. Some 1,200,000 employees are now covered by the charter. Some companies are even going further, calling on the help of Anact, the French national agency for the improvement of working conditions, to find ways of adapting the workplaces of sufferers to the constraints imposed by the diseases – unforeseen absences, treatment during working hours, bouts of fatigue, part-time work, etc. – rather than calling on the sufferer to adapt to the constraints of the workplace. But such cases remain the exception.

Outside of companies, the majority of schemes provide individual support within the context of medical/social or more specific psychological consultations. But the situation is changing, slowly but surely, with the role of collective approaches increasing. In many cases, these schemes are presented as “support groups”, in which goals, behaviour and various reference situations can be discussed. We can thus distinguish between self-help/support groups which give priority to discussions between peers and are mainly to be found in the third sector; “therapeutic education” groups often set up in a hospital setting; and psychotherapeutic groups in different shapes and sizes, whether psychoanalytic, systemic, behavioural or other.

**Clubs for speaking about illness and work**

Within this movement, an experimental “research/action” programme was conducted between 2010 and 2013, aimed at looking into the link between work and chronic illness. Financed by the National Cancer Institute (INCa) and the Cancéropôle d’Île-de-France, the programme was implemented by a team of psychologists and sociologists working for CNAM, the National Conservatory of Arts and Crafts in Paris. The goal of the programme’s “Clubs maladies chroniques et activité” is to better understand the obstacles in the way of letting a person return to work or retaining his/her work and to take action aimed at allowing a situation to develop in which work is done to the detriment neither of a sufferer’s health nor of a company’s business performance. To take part in such a Club, three conditions have to be fulfilled:

"Looking for a job is full-time work. (...) But when you’re ill, you’re tired and handle time differently.”

the person concerned must be of age, have a chronic illness and wish to resume work. It soon turned out that cancer was the disease accounting for most of the cases

"I needed routine support in dealing with my colleagues and managers", reported Corinne*, an employee in a stage of cancer remission. Like all participants, she had started by meeting the Club’s organisers, with a view to the latter finding out about her motives and explaining the approach. She then joined the group of working sufferers for 2.5-hour meetings once a fortnight. It quickly became necessary to distinguish between two groups: those with and those without a job. In both cases, at the start of any meeting, each participant gave a report on how things were going, to which the others could chip in: “That echoes my experience; ever thought of contacting a social worker?”, “Are you aware that Agefiph offers a disability allowance? That could help you pay for an Autolib to get to work?”, “You should go and see a lawyer. Your company has no right to do that!”; “Drop it. It’s not good for your health to be involved in a fight at the moment”; “In the sector I work in, that’s what I would do if I were you”; “Try to figure out what you can still do when you get so tired”; etc.

"What makes the Club so effective are the collective discussions. And the fact that we all have different illnesses; this avoids us moaning or comparing drugs. There’s not so much chance of getting dragged down", thought Isabelle, the former marketing assistant. “Being a member of this group helps me realise that we are not alone in having to face up to such situations”, affirmed Corinne. “And that we are not responsible for everything.” A number of participants spoke of the vitriolic coming from managers and employers. “It’s very good to have this opportunity to speak outside a home setting, where we don’t have to go into detail”, thought Corinne. “Peers don’t judge. As they’re all in the same boat, it makes discussions much more fruitful. They also don’t take pity on you, in contrast to certain friends who give advice.”

What sometimes also helps is to highlight the paradoxes in participants’ expectations, or to help people also realise that they might be adopting attitudes at work that do not facilitate relationships or about which they would otherwise complain. Corinne, who found herself shuttling back and forth between her company and her treatment, had for example decided to stop going to the company canteen for lunch. Instead, she ate a salad sitting in front of her screen to avoid losing time. "Describing this to the group, I realised that I was contributing to my isolation.” Changing her habits, she now finds herself better integrated in her new organisation, a smaller company than her previous one.

**Putting work in perspective**

Over and above information about whom to contact and useful schemes, on the right way to approach them and on ways to avoid being depressed in the face of the complex documentation to be submitted, the most frequent question relates to adapting to the new context, remarked Corinne, a jurist by training: “Participants realise that they cannot go on working the same way as always, that they have to adapt their work and their use of time to stay healthy. And that they have to change their lives.”

"The question of the meaning of the work also arises, with work no longer just a means of earning your living. You now have to look for ways of giving your work a meaning. You have to decide what your role is to be in the world, despite the fact that you might possibly die quite soon. Group participants are less able to cope with working conditions and jobs not in line with their ethics, but also with meaningless tasks, rules, idiots, all that wasted time”, recalled Nadine.

2. The association running the fund for integrating the disabled in the labour market.
3. An electric vehicle made available to Parisians via a car-sharing service. It ended on 1 August 2018.
“These discussions help to ‘de-privatiser’ the experience of being ill at work”

Interview with Dominique Lhuiller, professor emeritus in occupational psychology at the National Conservatory of Arts and Crafts (CNAM) and with sociologist Anne-Marie Waser from the “Clubs maladies chroniques et activité”. The two are co-authors of the book *Que font les 10 millions de malades ? Vivre et travailler avec une maladie chronique* (Érès 2016).

Interviews by Elsa Fayner

What gave you the idea of working in groups on this topic linking work and chronic illness?

I had worked before on the relationship between work and the adaptations necessary for those suffering from Aids. Visiting associations of sufferers, many of which has set up support groups, I saw the benefits of such groups. But even then, as many of these groups focused on just one disease, I found the discussions often revolving around forms of treatment, and rarely around work, despite the fact that many of these people, due to the progress made in treating their diseases, wanted to work. At the same time, I had spent many years leading workgroups on occupational practices. On the basis of all these experiences, we set up our “Clubs maladies chroniques et activité”.

Work is not just paid work

Reducing work to paid employment cuts it off from other forms of human activities. However, there is no preset dividing line between all these activities and paid work. Being ill transforms this system of activities, obliging people to set priorities reflecting both their aspirations and desires – desires in many cases adapted by the experience of the illness and the awareness of the finite nature of life – and the constraints and available resources. An investigation of the various activities makes it possible to get your bearings, making the most of all the experience and know-how gained in different spheres. This is the reason why the results of this research/action programme cannot be just reduced to changes in employment situations. It has a wider scope, enabling participants to start the long process of transforming both their lives and their surroundings with a view to living in reasonably good health.

What does this “double transformation” involve?

The “we” aspect is undoubtedly a key aspect for those enduring a disease all alone: when you just haven’t got any chance to talk with others, you tend to lose touch with reality and to get overwhelmed by doubts. Am I becoming mad? Am I making up what I feel?

The group appears as a space where the sick person finally has the opportunity to speak about things that are taboo in the lives of supposedly “non-ill” people. These discussions enable sufferers to ‘de-privatiser’ their experience of the illness at work, making it a subject around which to link up with others. They tend to invert the relationship with the illness, restoring the ability to act on it: we might then see expectations of help or support being replaced by efforts to transform one’s work and, going one step further, to transform work overall.

What limits have you come up across in the first few Club meetings?

We held some 50 meetings, at a rate of two a month. People were always coming and going, but on average six people usually attended a meeting. The majority (75%) were women between 21 and 60, half of whom were younger than 45, and 70% of them had upper secondary or tertiary education. This we see as a limitation: the social level of the participants was rather high.

The experiment has now finished. Will there be a sequel?

There already is a sequel! The City of Lille has contacted us, asking us to organise support groups focused on the conditions needed to keep people suffering from a chronic disease, an accident or a disability in work. This constitutes a new challenge, as the groups are organised within the regional authority.

Renunciations and commitments

Not having a job leads to further questions: should you tell a future employer about your illness, without knowing anything about the working environment in the company? Should you ask whether telework is possible, whether the working environment in the company? Should you tell a future employer about your illness, without knowing anything about the working environment in the company? Should you ask whether telework is possible, whether you just haven’t got any chance to talk with others, you tend to lose touch with reality and to get overwhelmed by doubts. Am I becoming mad? Am I making up what I feel?

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One tool of great help in such mapping was developed by an occupational psychologist involved in the Clubs’ work: a questionnaire designed to “get us to look at ourselves in the mirror”, remembered Nadine, “to find out how our previous experiences have marked us, our intangible values, the working conditions we liked”. This tool helped her sort herself out, to bounce back, “giving me new strength because you have nothing to set your sights on when you’re ill”. After having worked on it first by herself, then in the group, Nadine was able to come up with a job which she liked, working part-time as a counsellor in an organisation responsible for inserting people into the labour market in Seine-Saint-Denis – without any responsibility, with a lower salary and with superiors younger than her. “But I finally understood what counted for me: certain values and the opportunity to carry on working in a support role”. Three years later, the organisation shut down. In cancer remission, Nadine this time took her time to find a job taking her up to her retirement. Corinne is now back working in the legal sector, a sector she had to give up for a few years. And Isabelle has completely changed course and is now ... an occupational psychologist.