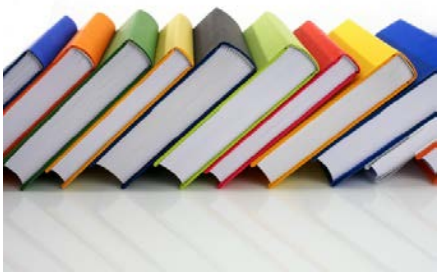
STROKE NETWORK *of* Southeastern Ontario

Returning to Work After a Stroke
Literature Review



INCIDENCE AND IMPACT OF STROKE

Stroke is a devastating disease and a leading cause of disability and death in Canada (Quality-Based Procedures: Clinical Handbook for Stroke (Acute and Postacute, 2016). This holds true in spite of advances made in stroke treatment and care. Each year, 62,000 Canadians will experience a stroke, equating to a stroke occurring every nine minutes (Heart and Stroke Foundation, 2017). Of those who suffer a stroke, 15% die, 10% recover completely, 25% recover with a minor impairment or disability, 40% are left with moderate to severe impairment and 10% are so severely disabled that they require long-term care (Quality-Based Procedures: Clinical Handbook for Stroke (Acute and Postacute, 2016). Annual costs to the Canadian economy are estimated at $3.6 billion (Quality-Based Procedures: Clinical Handbook for Stroke (Acute and Postacute, 2016).

Being young does not make one immune from stroke. International studies predict stroke rates among younger adults will double in the next 15 years (C.Campbell et al, Stroke in Young Adults, 2015). In Canada, 19% of hospital admissions for stroke and TIA are for younger adult patients between the ages of 20 and 59 and about four of every 100 strokes happen in people ages 18 to 45 (Heart and Stroke, 2017).

“Employment is regarded as one of the most important predictors of quality of life. People who are employed report a better quality of life, less health service usage and a better health status than non-employed people.” (van der Kemp et al, 2017). For most stroke survivors, moving from acute care to inpatient rehabilitation to community rehabilitation demonstrates progression in their recovery and increases their hope for the future. Community reintegration includes goals related to a return to former vocational, leisure and life roles (Heart and Stroke Foundation of Ontario, 2016). For many stroke survivors, this can include a return to work, especially for those within the younger age groups. “Being unemployed is associated with physical and mental health problems, while working has positive effects on the health of people with chronic conditions” (Balasooriya-Smeekens et al, 2016).

THE VALUE OF WORK

Employment is one of the most important social roles that a person fulfills and is a significant component of everyday life. Returning to work can positively impact various life domains including sense of identity, self-esteem, psychosocial wellbeing and improved long-term outcomes (Hackett et al, 2012; Martinsen et al 2013). Work engenders a sense of belonging and physical well-being and is important to developing and maintaining identity (Corr & Wilmer, 2003; Gilworth et al,2009; Medin et al, 2006; Vestling et al, 2005). Products of work include social contact and status and structure in one’s life (Corr & Wilmer, 2003). In fact, “employment is regarded as one of the most important predictors of quality of life. People who are employed report a better quality of life, less health service usage and a better health status than non-employed people.” (van der Kemp, 2017)

For stroke survivors, returning to work provides a boost in confidence and self-esteem. This milestone in their rehabilitation and recovery provides evidence of progress and is often the final hurdle to getting their life back (Corr & Wilmer, 2003; Japp, 2005). Individuals who return to work after stroke report significantly higher subjective well-being and life satisfaction (Gilworth et al, 2009; Hillman & Chapparo, 2002; Vestling et al, 2003) than those who don’t. Returning to work can reduce the sense of marginalisation following a stroke. (Martinsen, 2013). The ability to return to work provides the opportunity to move from dependence to economic freedom (Corr & Wilmer,

2003). The loss of work is one of the most significant problems patients and their families face following stroke. It results in an overall decrease in quality of life and contributes to financial problems, limitations in leisure and holiday activities, social isolation, and reduced self-efficacy (Wilz & Soellner, 2009). Not working has a substantial impact on overall health, and is a greater risk to health than heart disease. Not working has a similar effect to smoking ten packs of cigarettes per day (Radford & Walker, 2008). Observational studies suggest that while many stroke survivors are capable of working, a substantial proportion do not (Vestling et al, 2003). Rehabilitative medicine achieves only limited success supporting return to work (Giaquinto & Ring, 2007). Rehabilitation is perceived by many to be aimed at restoring function in activities of daily living and return to work is often overlooked (Medin et al, 2006, Treger et al, 2007). Studies also indicate that there is a lack of psychosocial support, information and rehabilitation services that are available to the needs of work-aged stroke survivors. (Martinsen, 2013) In an international review of 20 studies, it was determined that return-to-work rates after stroke ranged widely from 7% to 84% (Saeki, 2000). As well, the challenge moves beyond the return to work and also includes the challenges related to ensuring that individuals are able to remain in the workplace. Some individuals may return to work too early and only realize the effects that the stroke has on their capacity within the workplace once they have returned (Coole et al, 2012).

BARRIERS TO RETURNING TO WORK

Studies have identified a number of factors that have a negative impact on return to work (RTW) for stroke survivors. These factors are varied and include:

- impact of the stroke and residual deficits
- the approach used
- employer and work environment characteristics
- external factors
- coping strategies
- older age
- higher education level/white collar positions

Stroke can lead to a wide range of impairments, some of which are subtle and not well understood within the work environment (Chang et al, 2016; Lock et al, 2005). Neurological deficits have a significant impact on the possibility of returning to work (Treger et al, 2007). Overall stroke severity, as determined through the use of common clinical measures, is the most consistent predictive factor for return to work (Treger et al, 2007). Physical ability is also a critical factor. Side and location of the stroke, however, have limited impact (Lindstrom et al, 2009; Treger et al, 2007; Wozniak et al, 1999). Persistent symptoms that impact the ability to return to work include headaches, irritability, impaired ability to concentrate, and losing train of thought (Gilworth et al, 2009). Subtle cognitive deficits, such as deficits in working memory, mental speed and flexibility often go unnoticed but adversely affect return to work (Treger et al, 2007). It has been suggested that system pressures to reduce lengths of stay in hospital can result in the “needs of people with milder strokes or hidden deficits (such as impaired insight, executive dysfunction, anxiety and fatigue)” being frequently overlooked (Coole et al, 2012).

In addition, fatigue and memory disturbances often worsen with the physical or mental effort required in the workplace. Chronic fatigue is a common experience post-stroke and may result in a stroke survivor determining that work is too demanding (Corr & Wilmer, 2003). “ Fatigue was found to be associated with a decreased likelihood of RTW even ≤2 years after stroke. Psychiatric morbidity after stroke has also been shown to reduce the likelihood of RTW, particularly in patients who appear functionally intact or of limited physical disability” (Harris, 2014). Post stroke depression is associated with both a bad general outcome and absence of return to work (Alaszewski et al, 2007). Agnosia (cognitive disorders including visual inattention) and apraxia (inability to carry out familiar purposeful tasks) are significant negative factors (Saeki, 2000). In many work situations, the individual must receive, remember, sort and process information quickly and simultaneously and to make adequate decisions. Lack of concentration, speech deficits, and inability to multi-task frequently interfere with successful return to work (Alaszewski et al, 2007).

Medin et al (2006) identified three themes that covered the main barriers of successful return to work: the process, the individual and level of social support. The lack of individually designed rehabilitation programmes that include return to work as a goal, is apparent (Lindstrom et al, 2009). As well, the absence of clear guidance about when to return and how to achieve this has left some stroke survivors in limbo (Gilworth et al, 2009). For others, the process is haphazard and not well supported. This, along with uncertainty about timing of return to work and worries about inability to cope with persistent symptoms has impaired the return to work process (Gilworth et al, 2009).

For the stroke survivor, personality and view of life (optimism vs. pessimism) can influence vocational outcomes (Hofgren et al, 2007). For some individuals who had prior health problems, adjustment to their altered functional status acted as a barrier to returning to work (Alaszewski et al, 2007). Stroke survivors who did not experience a successful return to work often held the view that information and support were not forthcoming and that not all possibilities or alternatives had been explored (Gilworth et al, 2009). Individuals who experience fatigue, lack of concentration, and/or depression, identified the need for more information about the consequences of these cognitive deficits. This would have enabled them to return to work feeling better informed and would have diminished their fear of failure. Not having someone to talk to about the transition from rehabilitation to independence resulted in a negative outcome (Gilworth et al, 2009). Finally, apprehension about the process of return to work was more evident after a longer absence.

Support from employers and work environment characteristics have a significant impact on stroke survivors returning to work. Many employers do not fully understand the effects of stroke nor are they flexible in supporting stroke survivors to return to work (Corr & Wilmer, 2003). Stroke survivors identified that employers' negative attitudes, inflexibility and failure to implement adaptations to their work role, hours or equipment are barriers (Lock et al, 2005). This was most evident when supervisors lacked confidence in the rehabilitation and return to work process. In addition, an unstable work environment characterized by change and downsizing was an obstacle. Characteristics of the work and the adaptability of the individual workplace influence return to work. White-collar workers, for example, are more likely to return to work successfully following a stroke (Alaszewski et al, 2007). Stroke survivors' perceptions of the work environment, especially colleagues and managers' understanding of their situation, are important. Return to work was difficult when co-workers and managers were perceived to not acknowledge the situation and to be unsupportive (Alaszewski et al, 2007).

Finally, there are factors limiting return to work that are external to the stroke survivor, the approach used or their workplace. These include:

- architectural barriers, especially for stroke survivors with hemiplegia
- lack of suitable transportation
- poor local economy, with high numbers of unemployed, and
- stereotypes against disabled persons, such as being unprofessional, habitually absent from work and difficult to dismiss (Busch et al, 2009; Treger et al, 2007)

Unfortunately, mitigating or minimizing some of these factors requires considerable effort, while others are beyond our control.

ENABLERS FOR SUCCESSFUL RETURN TO WORK

The literature identifies several factors that contribute to a successful return to work for stroke survivors. Overall, a rehabilitation culture which encourages early return to work, even if recovery is still ongoing, needs to be promoted. Stroke survivors need to be fully engaged in the return to work process and in the decisions that are made about their working life (Gilworth et al, 2009). The attitude and motivation of the stroke survivor is key. A positive attitude, self-confidence, determination, assertiveness and motivation are all important (Lindstrom et al, 2009; Radford & Walker, 2008). Alaszewski et al (2007) found in their study that some participants had developed a resilient approach to illness. They recalled previous experiences dealing with challenges to their well-being and drew from these strategies again following stroke. For these individuals, returning to work had a special significance. It was a way of showing that they were progressing and returning to pre-stroke normalcy. They took

control of their situation, discussed how to facilitate their return to work, and found new strategies when a work trial was not successful. There is evidence that return to work is influenced by individuals' perceived self-efficacy and support from family (Busch et al, 2009). Family members are prime sources of support and can enhance the motivation and determination demonstrated by the stroke survivor, "…the support from one's family, friends and co-workers appears to be an important, positive influence on a patient's decision to return to work after a stroke" (Bonner, 2015). As well, boredom has been identified as a motivator for return to work by a number of stroke survivors. "The fear of not knowing what to do at home all day can be a motivating factor for return to work because staying at home may result in social isolation due to loss of the socialising effect at the workplace" (Ntsiea, 2014).

Obviously, the residual deficits from the stroke are impactful. Preserved cognitive capacity was found by some authors to be the best predictor of returning to work (Treger et al, 2007; Vestling et al, 2003; Wozniak et al, 1999). It has been suggested that the "cognitive screening of patients with mild-to-moderate stroke should receive more attention, so that patients with mild cognitive impairment can be better supported in returning to work from a very early period on, e.g., by learning compensational strategies" (van der Kemp, 2017). Additionally, "having invisible impairments was sometimes described by patients in relation to normality, as looking normal but not feeling normal. The contrast between looking and sounding normal from the outside and the presence of fatigue and other invisible impairments often led to difficulties, and a lack of understanding by others…(Balasooriya-Smeekens et al, 2016). The ability to perform activities of daily living, as measured by the Barthel Index, is consistently associated with successful return to work after stroke. Wilz and Soellner (2009) found that the individual's perceived functional ability is the most important predictor.

Job characteristics are an important predictor of successful return to work. Relatively inexpensive and simple interventions, such as a phased return to work and flexible working hours can have a significant impact on the transition back to work for some people. Medin et al (2006) found that a stable work environment that encouraged the individual and made them feel safe and secure is important. This allowed return to work to be a gradual process in which the stroke survivor increased their work ability and workload incrementally (Gilworth et al, 2009). People with higher incomes, more education and more skilled forms of employment have a greater probability of returning to work after a stroke (Corr & Wilmer, 2003; Lindstrom et al, 2009). Blue-collar workers tend to return to work earlier than white-collar workers, but over a longer time period, white-collar workers are more likely to experience success (Alaszewski et al, 2007; Treger et al, 2007; Vestling et al, 2003; Wozniak et al, 1999). The availability of alternative jobs and/or education and re-training also has an impact (Locke et al, 2005). Support from co-workers who expressed understanding and an encouraging attitude is also beneficial (Alaszewski et al, 2007; Corr & Wilmer, 2003).

Liaison between rehabilitation professionals and employers is considered an important factor in enabling access to appropriate services and a successful return to work (Alaszewski et al, 2007; Lock et al, 2005). This relationship enhanced employers' willingness to recognize complex and hidden post –stroke impairments, such as fatigue and cognitive problems , and to provide workplace accommodations (Alaszewski et al, 2007; Gilworth et al, 2009). As well, 'there is a reduced probability of RTW for survivors if it does not occur within the first year after the stroke" (Harris, 2014). Coole et al (2012) found that "employees with stroke may be unable or unwilling to identify their needs and limitations or struggle to communicate them effectively, for a range of possible reasons…These include speech problems, lack of insight or a high motivation to return to/remain at work for reasons of, for example, to benchmark their recovery, guilt at burdening colleagues, financial insecurity and fear of losing their job. Decisions made concerning risk assessment, work accommodations such as altered hours and duties, and monitoring of performance may therefore be inappropriate or inadequately applied."

In a study by Corr & Wilmer (2003), three key factors were identified as impacting successful return to work following stroke:

1. motivation to return to work or reasons why returning to work was an important goal for them,
2. return to work experience itself which was impacted by the attitudes of their employer and fellow employees, and
3. support in returning to work.

The type of support that stroke survivors seek includes general advice, specific skill development if needed, support for a gradual return to work and longer follow-up support in the workplace (Corr & Wilmer, 2003; Lindstrom et al, 2009). "…most employers' experience of stroke occurs when employees who have had a stroke return to work. Employers therefore have little prior experience to guide them and as stroke affects individuals differently, any previous experience is not necessarily transferable" (Coole et al, 2012) In fact, employers may be also be concerned with their own mortality in light of the employee's stroke. In Coole's study, "participants described a sense of shock and disbelief in response to an event that was sudden and unexpected" (Coolet et al, 2012). Employers referred to "several personal qualities and characteristics of the employee with stroke which were associated with their return to work. Those important to the participants included that the employee had a good work ethic and a positive outlook, was hard-working and held a responsible job. Not being 'too old' was seen as an advantage although a long history of employment with the company was also viewed positively. Other characteristics seen as beneficial were that the employee liked their job, fitted in well with the team, were easy to work with, were enthusiastic and popular and had a good relationship with their manager" (Coole et al, 2012).

SUPPORTING RETURN TO WORK

Vocational rehabilitation is a supportive stepping stone which prepares the stroke survivor to enter or return to employment (Japp, 2005). **"**Vocational retraining is not usually a feature of post-stroke rehabilitation and emerging evidence suggests that a separate process is required to optimise return to work opportunities. Research evidence suggests that the key features of vocational rehabilitation should include workability assessment, work visits, involvement of the employee, health professional and employer and early intervention" (Ntsiea et al, 2014). Rehabilitation professionals need to be aware of the importance of employment to good health and are in a unique position to facilitate the return to work process (Trigger et al, 2007). They need to empower the stroke survivor and enhance their ability to create solutions to problems that arise (Medin et al, 2006). Evidence suggests that vocational rehabilitation interventions need to be targeted early (Radford & Walker, 2008). It may be initiated before the individual leaves an acute stroke unit, rehabilitation unit and certainly before discharge from community stroke rehabilitation services.

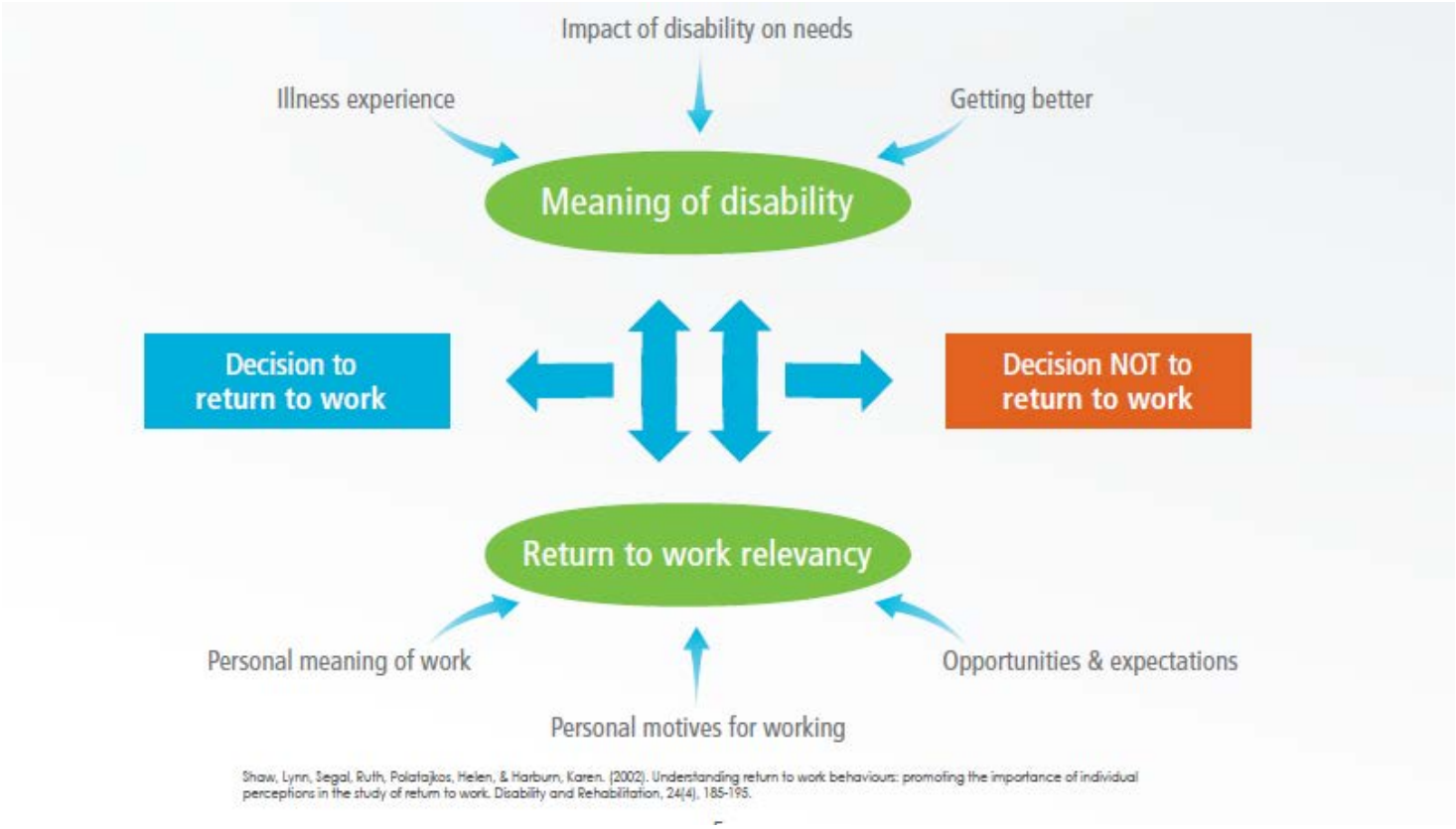
Successful return to work after stroke requires an inter-professional approach and is unique for each person (Giaquinto & Ring, 2007; Saeki, 2000). Components of a successful return to work strategy include clear vocational goal setting, addressing biological, psychosocial and social issues, and an individual approach (Radford & Walker, 2008). Vocational assessment determines whether the individual has the capacity to return to work. It identifies aptitudes and workplace competencies that will determine whether the stroke survivor can return to their former job or require an altered work position or new position (Japp, 2005).

Research by Ownsworth & Shum (2008) identified the need to assess executive functions following stroke to assist in identifying potential barriers to participating in productive activities and to inform rehabilitation planning. These executive functions include the capacity to form a plan of action, initiate behaviour, think flexibly, solve problems and self-monitor and self-regulate behaviour in any given environment.

Rehabilitation is designed to enhance the individual's skills, thereby maximizing his/her potential to return successfully to work (Alaszewski et al, 2007). Consideration must be given to the factors influencing vocational outcome after stroke when targeting return to work interventions (Busch et al, 2009; Vestling et al, 2003). Any return to work program should enable the development of skills, enable opportunities for retraining and promote links to employers (Corr & Wilmer, 2003).

Vocational rehabilitation should provide gradual exposure to increasingly complex work tasks at a pace that enables the stroke survivor to maximize their occupational potential. It allows the health care professional to gain insight into any difficulties while providing the support and encouragement needed to adapt (Japp, 2005). Return to work is a complex process that requires a broad understanding of all relevant factors (Shaw et al, 2002). A better understanding of the variations in return to work is achieved by being aware of the subjective perceptions of

the meaning of disability and the relevancy of return to work. In contemplating a return to work, stroke survivors will consider these within the context of their current situation (Shaw et al, 2002). According to Shaw et al (2002), the "meaning of disability" is determined by the individual and their beliefs and perceptions of how their impairments impact their current and future abilities to engage in activities. This process results in a significant variation in return to work experiences. "Vocational rehabilitation programs facilitate early RTW for persons with temporary or permanent disabilities. It is usually recommended that vocational training should be gradual, starting with part-time work and then successively increasing to longer working hours. Persons with injuries or illness who are offered modified work programs RTW twice as often as those who are not. The importance of active participation by the stroke survivor in all aspects of the management of the RTW process as well as a stroke educator/workplace advocate has also been stressed" (Vestling et al, 2013)



Shaw, Lynn, Segal, Ruth, Polatajkos, Helen, & Harburn, Karen. (2002). Understanding return to work behaviours: promoting the importance of individual perceptions in the study of return to work. Disability and Rehabilitation, 24(4), 185-195.

In considering their illness experience, reactions to their disability are derived from previous illness experiences, their illness beliefs, and pre-stroke perceptions of self. Consideration is given to the stigma associated with not working, response from others who question the validity of the disability, and the process of having their disability determined by the medical and insurance systems. The impact of the disability is identified through the daily losses they experience in meeting their own basic needs. Through the process of getting better, stroke survivors can understand their prognosis and their capacity for working. Getting better includes many strategies: gaining new information, trialling various recovery strategies, using these strategies to develop new work skills and minimize disabilities, determining physical, mental and work capacities, and using available supports. Vestling suggests that "every individual has his/her own personal way in adapting to work, similar to a learning process and the motivation was triggered by different subjective meanings of work. The individual's motivation is often the key for success which is why this needs to be greatly emphasized in all rehabilitation" (Vestling et al, 2013).

"Return to work relevancy" is determined by reflecting on the personal meaning of work and their motives for working, and by considering opportunities for work and workplace expectations. The meaning of work is based on

the stroke survivor's sense of identity with work, work ethic, emotional attachment to work, and by family/society's work values. This helps them to understand the personal impact of not returning to work. Personal motives for working include the meaning and importance of work to the individual, financial incentive and goals related to personal growth. Finally, stroke survivors consider a number of factors as being either relevant or not relevant to their return to work, including available opportunities, workplace expectations and any workplace concerns they had prior to their stroke (Shaw et al, 2002).

In their clinical practice guideline, "Management of Adult Stroke Rehabilitation Care," Duncan et al (2005) have made the following recommendations for encouraging and supporting stroke survivors to optimize their potential to return to work:

- All stroke survivors, if their condition permits, should be encouraged to be evaluated for the potential of returning to work;
- All stroke survivors who were previously employed, should be referred to vocational counselling for assistance with the return to work process;
- All stroke survivors considering a return to work but who may be experiencing a lack of motivation, or who have emotional and psychological concerns, should be referred for supportive services.

Physicians and other rehabilitation professionals need to recognize and acknowledge that stroke survivors are individuals who have many roles including worker, spouse and family member. It is essential that information and advice to facilitate return to work is provided at the earliest opportunity (Gilworth et al, 2009). It should be noted, however, that for some people, stroke did change the meaning of work and included some undesirable elements, in particular, stress. These individuals perceived that work caused stress and that stress was a contributing factor in their stroke (Alaszewski et al, 2007). Therefore, a client-centred approach must be used when supporting a stroke survivor with return to work. This enables the flexibility to change goals and strategies as the stroke survivor works though the process (Corr & Wilmer, 2003). "If people were able to cope with their impairments, this sometimes led to a more positive experience at work. Some people reported that once they had accepted their changed abilities, and 'listened to their body', paced their work, or were 'patient with themselves', it became easier to deal with their impairments and day-to-day activities" (Balasooriya-Smeekens et al, 2016)

Original Return to Work Literature Review compiled by Donna Scott, Interim Coordinator for Community & Long Term Care, SWO Stroke Network. Edited by Megan Cornwell, Communications Consultant, Southwestern Ontario Stroke Network August, 2010. Additional references provided by Stroke Network of Southeastern Ontario, March 2018.

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This information is provided by the **Stroke Network of Southeastern Ontario Stroke Network** and is based on the work of the **Stroke Network of Southwestern Ontario's Return to Work After Stroke Working Group.**