

Burn Rehabilitation Services at **Sunshine Social Welfare Foundation**

Message from the CEO



Ching-Shyen SHU CEO

hen Sunshine Social Welfare Foundation established its Rehabilitation Center in 1991, it became the first community-based center specialized in burn rehabilitation in Taiwan. Over the last 20 years, physical rehabilitation services of Sunshine have had a tremendous impact on the lives of burn survivors, making the difference between lost capacities, wasted opportunities and the ability to live a full, independent life. We hope that this introduction will help you understand the particular characteristics of our physical rehabilitation services, as well as their importance in providing comprehensive burn care to burn survivors.

Foreword



Vita Yu-Hsien TU
Director
Sunshine Rehabilitation Center

hile preparing this introduction to the burn rehabilitation services of Sunshine Social Welfare Foundation, I realized how far we have come. Twenty years ago, Sunshine Rehabilitation Center only had one part-time staff but now, it has 12 therapists across Taiwan. I didn't witness the first 10 years of the Center, but I am well aware that many people supported Sunshine and many more needed Sunshine's service. This is still true today. If Sunshine didn't have the Rehabilitation Center to offer specialized burn rehabilitation services, I really don't know where these burn survivors would go.

A burns is perhaps the most destabilizing event to occur in one's life. When burn survivors arrive at the Rehabilitation Center with physical and emotional pain, they might not be actively seeking help and instead, they might just be following the natural course of treatment after burns. However, we see progressive change: they laugh more, their movements become more agile, they speak with more vitality. Every once in a while, burn survivors will tell me: "I'm very grateful to Sunshine Foundation! If it wasn't for Sunshine, I might still be hiding at home and who knows what I would become?"

The Center doesn't have a magic wand to transform burn survivors. What we offer though is a place to exchange knowledge about burn rehabilitation, to let burn survivors share their stories of hardship and pain, to give impetus to motivation to move forward and allow burn survivors to leave transformed. The work of Sunshine staff, the support of society and the vision of our predecessors who established the Rehabilitation Center made this possible.

Any meaningful endeavor involves difficulties, but it is those difficulties that make everything worthwhile. To the social workers and psychological counselors: thank you for accompanying burn survivors through their emotional ups and downs; to the therapists: thank you for getting angry when burn survivors are too lazy; to the daily living assistants: thank you for keeping the Center tidy and taking care of everyone's needs; to the administrative staff and assistants: thank you for your wonderful work. Beautiful stories are made possible at the Rehabilitation Center because of you all.

Taiwan's first specialized burn rehabilitation center





Evolution of a dream

hen Sunshine Foundation was established in 1981 by a group of public-minded individuals, it aimed to address the many issues faced by burn survivors and people with facial disfigurement, one of which was the burn survivors' need for adequate physical rehabilitation. Indeed, as early as 1983, Sunshine identified the necessity of setting up a "therapy room" where burn survivors could do rehabilitation together under the supervision of a therapist. Although this idea could not be brought to fruition immediately, it nonetheless evolved over the next seven years. From a simple "therapy room," Sunshine began to dream of setting up a center where all the rehabilitation needs of burn survivors could be met in a comprehensive manner. A tragic event would suddenly make this dream possible.



Finding a way to answer the needs of burn survivors after a tragedy

n April 1990, a major explosion in the Hung-Kuang factory lead to the death of 40 people and severely injured 29 others. At that time, burns were not covered by Labor Insurance, and before the implementation of universal health insurance in 1995, all medical costs were shouldered by patients themselves. These financial considerations, as well as other difficulties (lack of motivation, transportation issues, etc.) often meant that after hospital discharge, burn survivors did not follow with physical therapy.

What is now known as "Hung-Kuang Incident" was one of the biggest industrial accidents to occur in Taiwan. The scope of the tragedy moved the public to donate for the victims and as one of the recipients of funds, Sunshine decided to focus on helping burn survivors in the long-term by using the money to set up a Rehabilitation Center that would specialize in offering sustained, intensive burn physical rehabilitation.

Taiwan's first specialized burn rehabilitation center







Overcoming protests to establish a community-based rehabilitation model

hen Sunshine decided to set up the Rehabilitation Center in a residential area of Taipei, the logic was simple: benefit from proximity with major medical centers in the greater Taipei area, and facilitate social reintegration of burn survivors by being directly in the community.

However, residents quickly mobilized to protest, arguing that the Center would devaluate their properties, neighborhood safety would be jeopardized, the Center would spread diseases and the normal development of their children would be affected by seeing so many people with disfigurement.

All of these fears and prejudices stemmed from a lack of awareness towards burn survivors, and Sunshine tackled them one by one. Although the Center officially opened in 1991, Sunshine engaged in dialogue with residents, holding between 1990 and 1992 over 60 community meetings to address their every concern, gaining their trust and acceptance in the process, as well as improving their understanding of burns and facial disfigurement. As community relations improved, Sunshine also held many activities to strengthen ties between burn survivors and residents.

In order to accommodate a growing number of clients, Sunshine moved the Center to bigger facilities in a commercial district in Taipei in 1994. The original facility then became a dormitory, offering short-term housing services to burn survivors from other regions coming to Taipei for rehabilitation.

The Center remains a successful example of community integration and this experience later enriched Sunshine's other efforts to break down barriers to the social participation and inclusion of burn survivors.

Helping

burn survivors start anew







When a person has a serious accident, like a major burn, it is as if your entire life is brought back to zero. You will have to re-learn a lot of things from scratch, such as how to eat, how to talk, how to interact with others. But back to zero is not quite like going back in time, instead, it is more like starting your life anew, with your scars.

Vita Yu-Hsien TU, Director,
 Sunshine Rehabilitation Center

« Transformation », Impressions of Happiness

Comprehensive burn rehabilitation services

very year, Sunshine Foundation's Rehabilitation Center provides rehabilitation services to an average of 50 to 60 clients. Most clients suffer from severe burns (over 50% of their body surface) and require on average ten months of intensive rehabilitation. Some come in wheelchairs, unable to walk. Others come with hands severely contracted by scars, unable to eat or care for themselves. Some arrive immediately after hospital discharge, others arrive after having spent weeks or even months at home. All feel like they have loss control over their body and their life, all worry about the future.

The seven therapists and two care assistants of the Center help burn survivors in their effort to control scars and regain the ability to live independently. Rehabilitation schedule is intensive: Monday to Friday, from 9:30 to 16:30. An individual rehabilitation program will include wound care education, reconditioning exercises, ROM exercises, functional activities, splinting and ADL training.

Therapists work as part of the multi-disciplinary team of Sunshine that includes social workers, psychological counselors and vocational counselors. Together, these professionals will address the physical, psychological and social needs of burn survivors.

Helping burn survivors start anew







The long road home of A-Hui and her mother

or burn survivors, leaving familiar home surroundings and the protection of family to embark in the long battle against their scars at the Center can be scary and daunting. Family members might feel conflicted when comes time to making the decision, hesitating between the need to encourage their loved one on the road to recovery and the desire to protect them from further hardships.

When A-Hui finally decided to bring her injured mother from southern Taiwan to the Rehabilitation Center in Taipei, she had already been lying in bed in a nursing home for eight or nine months. Having lost all functions in her arms and legs, she couldn't do anything by herself. Having lost hope and the will to live, she believed that she would spend the rest of her life in this hospice bed.

The therapist at the Center spent time explaining to mother and daughter the challenge that lay ahead, convincing them that for the mother to recover, all three of them would have to work as a team and be relentless.

A-Hui saw first hand the pain of rehabilitation. Thick scars and loss of muscle strength made it almost impossible for her mother to stand up for 20 seconds. Held by A-Hui and the therapist, her mother struggled, screaming and crying in pain, all the while counting from 1 to 20. A-Hui had to get a grip on herself, and not weaver in her resolve to help her mother despite seeing her in so much pain.

Her mother had to re-learn everything: eating, drinking, walking, standing up, climbing stairs by herself. After one round of exercise, she would say: "Let's do one more!" The belief of Sunshine's therapist that recovery is possible was transmitted to A-Hui and her mother. Soon, A-Hui's mother was able to stand up and count to 30, then 40, then 60... Eventually, she was able to stand for long periods of time and walk by herself.

The recovery of A-Hui's mother is not a miracle, it is literally the result of blood, sweat and tears. With the support of A-Hui and the encouragement of the therapist, she was able to overcome the disabling physical and emotional effects of months of immobility and regain the ability to live independently.

Professional involvement that goes beyond

physical rehabilitation



Although you all thank Sunshine, this is not what is most important to us. What we want is to see progress in your hand function; we want to see you be able to raise your legs higher. We are not your family; we are just passers-by in your life so we have no right to criticize you. But sometimes we can't help feeling angry and anxious when we see you chatting instead of doing your exercises...

- Shi-Yuan HUNG, Occupational Therapist
Sunshine Rehabilitation Center

Ithough the Center focuses on the physical rehabilitation of burn survivors, it also plays an important role in their psychosocial rehabilitation. The long period of rehabilitation of burn survivors and their close interaction with occupational and physical therapists make it possible for a psychological support system to emerge.

Physical rehabilitation is painful. Some burn survivors will cry, become upset or want to give up. To keep them motivated, therapists have to alternate between playing the role of "good cop" and "bad cop." Although therapists cannot share their pain, they always seize opportunities to encourage burn survivors: "Don't worry; it will get better day by day." "It might hurt a lot now, but don't let the pain keep you from getting better." Sometimes, when burn survivors lag in progress, therapists will become serious and reprimand burn survivors, pointing out the dangers of becoming too lazy.

Therapists are confronted to the burn survivor as a whole person, someone who not only faces physical pain and impairment, but also emotional distress, perhaps even family or financial difficulties that might influence motivation to carry out rehabilitation. Apart from coordinating with social workers and psychological counselors of the Foundation to monitor the psychological well-being of burn survivors, therapists also organize activities to help burn survivors adjust to their daily rehabilitation program.

Monthly outings such as going to the movies aim to relieve the stress of dealing with other people once burn survivors step out of their regular surroundings. And the Center organizes annual rehabilitation awards to recognize the efforts of burn survivors. This encourages burn survivors on their way towards recovery, and also facilitates sharing of experience between them.

A place where comradeship develops



When I arrived at Sunshine Foundation, I saw many people just like me, with some of them having sustained injuries worse than mine, but they all grit their teeth and did their physical therapy program. A burn survivor once told me: 'If you don't do physical rehabilitation, you won't be able to live the rest of your life.' These words stunned me: 'True! I don't want to miss out on the rest of my life! I will make efforts!

- Mei-Hsing YEH, burn survivor "Rebirth", Impressions of Happiness hen burn survivors come to the Rehabilitation Center, they meet many others who have been through similar experiences. The fact that they will do physical therapy together every day over a long period of time means that they will naturally forge bonds and develop a feeling of comradeship. This comradeship is an important source of support and encouragement for burn survivors during the painful process of rehabilitation. They cry together, they joke together, they laugh together and encourage one another.

During hospitalization, orders from doctors and nurses might sometimes sound harsh to the patient. At the Center, therapists might sometimes sound a little bit too strict when overseeing progress. But when a senior burn survivor reminds a newcomer to wear his pressure garment or to use his splint otherwise scars will grow and contract, these words of advice are more readily accepted, because they stem from experience. And when burn survivors who graduated come back to the Center to tell their peers that life indeed gets better after burns, their words give hope.

Comprehensive assistive device services to

support rehabilitation



part from daily physical and occupational therapy, burn survivors also rely on assistive devices and techniques for their rehabilitation. Some, like pressure garments, have an obvious therapeutic effect, while others, like skin camouflage and facial prosthesis, can help enhance burn survivor self-confidence by attenuating differences in their appearance



Pressure garment

ressure therapy – wearing of tight, elastic pressure garments – to prevent and control the formation of hypertrophic scars is an important component in the treatment of burns. Except when eating or taking a shower, burn survivors must wear these garments all day, sometimes for up to two years. As such, therapeutic effect and comfort are two major concerns.

In 1998, Sunshine made the decision to start developing its own pressure garment production service in order to provide burn survivors with affordable, comfortable yet efficient garments. Since then, therapists of Sunshine have developed custom-made production techniques and oversee measurement, production and fitting. Evaluation by therapists is carried out before and after the garment is made. This follow-up process ensures quality and a perfect fit, and it is also important to help the patient adapt to this new garment.

Comprehensive assistive device services to

support rehabilitation



Before



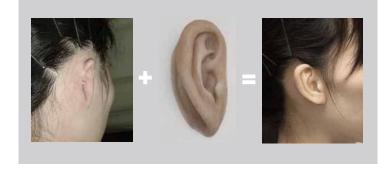


Skin camouflage

Ithough plastic surgery can help correct disfigurement, it cannot make scars, discolorations or marks totally disappear. Burn survivors must go through the difficult process of learning to live with their scars and their different appearance, but also learn to deal with the reactions of strangers. This adaptation process can sometimes be facilitated thanks to special make-up techniques that can attenuate or conceal visible differences.

Sunshine launched in 2002 its skin camouflage service, offering free consultations to burn survivors and people with facial disfigurement. Apart from teaching clients make-up techniques during individual consultations, the Foundation also organizes group activities focusing on image enhancement (hair styling, fashion consultation) and social skills training.

For some clients, skin camouflage is a temporary solution used during the transition period when burn survivors build the confidence to face the world. For others, it becomes part of their daily routine. Either way, skin camouflage is much more than just make-up, it is a tool that can support burn survivors in their psychosocial rehabilitation.



Facial prosthesis

he facial prosthesis service of Sunshine was launched in 2007 and serves a similar purpose as skin camouflage: give burn survivors and people with facial disfigurement the tools to manage their appearance and in the process, give them confidence to face others. Therapists of the Rehabilitation Center can help clients produce custom-made ear, nose or eye prosthesis.

Promoting

burn rehabilitation with professionals







Because the Rehabilitation Center has been able to focus exclusively on burn rehabilitation for over 20 years, it has accumulated extensive experience which not only benefits burn survivors, but is also being shared with rehabilitation specialists across Taiwan.

The Center organizes every year a variety of lectures, trainings and workshops that focus on teaching the principles of burn rehabilitation and scar management, as well as techniques for producing splints or pressure garments. These trainings are

open to any physical and occupational therapist interested in learning more about burn rehabilitation. Therapists of the Center are also invited as speakers during in-house training organized by hospitals for their own burn center/unit staff.

The Center is also becoming a place of training for future therapists. Not only does it welcome university students in occupational and physical therapy for study visits, but it has also started providing internship opportunities.

Delivering

rehabilitation services to burn survivors across Taiwan



Ithough Taiwan is relatively small, burn survivors are scattered across every county and city, in urban, rural and mountainous areas. Ensuring that every burn survivor has timely and easy access to services has been a priority for Sunshine Foundation, which over the years established service centers in central (Taichung, 1990), southern (Kaohsiung, 1996; Yun-Chia, 2010) and eastern Taiwan (Hualian, 2001). Although primarily staffed with social workers to coordinate services and link clients to resources, these centers were from the start also concerned with physical rehabilitation.

At the beginning, centers like those of Taichung and Kaohsiung built a local network of rehabilitation resources, creating partnerships with hospitals or clinics able to provide burn rehabilitation. However, not all burn survivors have the resources or ability to go back regularly to hospital to do rehabilitation. Also, social workers found that with time, motivation to do rehabilitation decreased, leading to serious complications.

That is why in 2004, the center in Taichung launched a home rehabilitation outreach program, where social workers are accompanied during their home visits to burn survivors by a therapist who carries out evaluation and plans a rehabilitation program, oversees progress and supervises pressure garment therapy. The therapist also educates clients and family members about the importance of physical rehabilitation. This outreach program not only ensures that the physical progress of burn survivors is not interrupted after hospital discharge, but it also helps identify problems in time and propose immediate solutions, thus reducing disabling complications that can otherwise be prevented. Home visits by social workers and therapists are also an important source of emotional support for burn survivors.

The home rehabilitation program developed in Taichung has become the template for the regional outreach project of Sunshine Foundation, and has been implemented in all the other regional centers. To this end, the regional centers all have at least one therapist (OT or PT) on staff to carry out home visits.

Oral cancer rehabilitation services







n 2006, Sunshine Foundation launched its comprehensive services for oral cancer survivors. This strategic decision to expand services for this particular group was made necessary by the scope of the problem¹, but also by the fact that in the majority of cases, oral cancer treatment results in facial disfigurement. As is the case with burns, Sunshine's intervention begins after hospital discharge. Through comprehensive physical, psychological and social rehabilitation, Sunshine aims to help oral cancer survivor gain a better quality of life and achieve greater social participation.

Oral cancer results in many physical problems: reduced movement in the maxillo-facial and neck areas, uncontrollable salivation, reduced speech functions, inability to eat solid food, stiffness and pain, etc. These physical problems greatly affect quality of life not only because of the physical discomfort they create, but also because they end up limiting social participation of oral cancer survivors. Unable to speak clearly or control their salivation, they become increasingly self-conscious, isolating themselves and unwilling to go out and meet people.

To address these issues, the Rehabilitation Center offers oral cancer survivors specialized physical therapy services. Through massages and exercises, stiffness can be reduced, movements can improve, and oral cancer survivors can have better control over salivation and speech functions. In turn, these physical improvements allow oral cancer survivors to be able to live more active lives.

¹ Figures from the Department of Health show that every year, 5,781 people are diagnosed with oral cancer in Taiwan, and in 2010, 2,370 people died of the disease. There are currently 33,594 people undergoing treatment for oral cancer. The disease predominantly affects men aged between 45 and 55 years old, and is linked to the habit of chewing betel nut (areca nut).

Sharingburn rehabilitation experience with the world







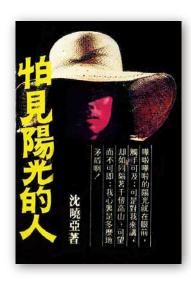


ctober 2011 marked a milestone in Sunshine Foundation's development, as it carried out its first international cooperation project. Indeed, a team composed of staff from the Rehabilitation Center held a four-day training program in Nicaragua designed to teach burn professionals in the Central America region pressure garment production techniques.

It is not a coincidence that Sunshine's first international cooperation project focused on burn physical rehabilitation. Low and middle income countries have a higher incidence of burns, and the outcome for burn survivors is often affected by a lack of medical resources or expertise. As professionals in these countries strive to provide better medical care for burn survivors during the acute phase, they also become concerned with post-burn rehabilitation. With its 20 years of experience, Sunshine Rehabilitation Center is in a good position to share knowledge and expertise with international partners looking to better the quality of life of their patients and clients.

The training program in Nicaragua is a start, and will serve as a model to further develop international cooperation based on capacity building and knowledge transfer.

About Sunshine



sunshine Social Welfare Foundation was established in 1981 by a group of individuals committed to improving the lives of burn survivors and people with facial disfigurement.

Sunshine Foundation has for mission "to provide an extensive range of services for burn survivors and people with facial disfigurement; to assist them in their physical, psychological and social rehabilitation; and to uphold their rights and dignity."

To this end, Sunshine Foundation brings together social workers, physical and occupational therapists, psychological counselors, vocational counselors and social educators, all cooperating as a team to provide comprehensive services to burn survivors and people with facial disfigurement. Services of the foundation include:

Financial aid that covers the expenses for medical treatment, rehabilitation, pressure garments, living and transportation.

Physical rehabilitation services such as physical therapy, occupational therapy, pressure therapy and the production of assistive equipment. Sunshine Rehabilitation Center, established in 1991, is the first center in Taiwan specialized in burn rehabilitation.

Housing services offering short-term accommodation for burn survivors in need of continuous rehabilitation in Taipei.

Psychological counseling services such as one-on-one individual counselling, group activities, play therapy and sand therapy.

Scholarships to encourage children and youths with facial disfigurement to pursue their studies.

Social education for the prevention of burns and for the social acceptance of burn survivors and people with facial disfigurement.

Vocational services to facilitate the reintegration of our clients in the job market and allow them to live full, independent lives.

ith five centers in Northern, Central, Southern and Eastern Taiwan, and 110 employees, Sunshine Foundation reaches out to burn survivors and people with facial disfigurement across Taiwan, servicing over 2,000 people every year.

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