

# Supporting Your Needs

## The Social Worker Role

### What Resources are Available to You



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# CF Clinic

- 🌹 All CF centers are mandated to have SW and it is recommended that patients be seen and screened a minimum of 1x per year
- 🌹 All patients are eligible for SW services. There is no cost and the service is optional
- 🌹 Goal is to optimize biopsychosocial functioning of CF patients
- 🌹 CF patients are vulnerable to social and emotional problems
- 🌹 Follow all adult CF patients in the CF clinic for ongoing mental health assessment
- 🌹 Counseling and support
- 🌹 Referrals for community resources

# SW support in the hospital

- 🌹 Follow all CF inpatients
- 🌹 Provide counseling and support to patients facing health crisis
- 🌹 Facilitate communication between hospital providers (including CF team) and patient
- 🌹 Coordinate care conferences as needed
- 🌹 Linkage to hospital and community resources (massage, guest services, parking, etc)
- 🌹 Assist patients facing significant change in health (hospice need, starting O2, diabetes, transplant listing)
- 🌹 SW is a common thread for patient across environments

# Compliance

- ❁ More than 50% of CF patients are significantly noncompliant in at least one aspect of management (P.E. Pfeffer et al, 2003)
- ❁ Incomplete adherence is considered normal and should be addressed openly and honestly between CF providers and patients
- ❁ SW provides assessment and counseling around problems related to compliance
- ❁ Important to acknowledge that there are multiple factors contributing to compliance
- ❁ Patient/provider relationship is essential in addressing compliance problems
- ❁ Devastating consequences, preventable
- ❁ Good compliance is essential to transplant listing

# CF and employment

- ✿ Increasing numbers of people with CF are living well into adulthood and require assistance with issues in the workplace
- ✿ Lack of appreciation of CF as a disability has created increased economic strain among CF adults who find themselves unable to work for health reasons
- ✿ People who work full time can feel stressed and overwhelmed with the additional burden of medical care, long clinic visits, and unexpected health crises
- ✿ FEV1 and age do not necessarily predict employment status (Burker et al, 2004)
- ✿ Time intensive medical regimen interferes with ability to work in a full time capacity

# Employment issues cont'd

- 🌹 There is an ongoing struggle for balance between good health maintenance and financial stability through work
- 🌹 SW provides coaching and counseling to patients around employment issues and assists with important decisions such as taking medical leave or beginning the process of applying for disability
- 🌹 Should I disclose my CF in a job interview?

# Disability

- 🌹 SW assists patients with disability process
- 🌹 **Social Security Disability Insurance (SSDI)** is a program that provides a monthly income and Medicare insurance for people with a work history who have become disabled due to their CF
- 🌹 **Supplemental Security Income (SSI)** is a program that provides a set monthly income and Medi-Cal coverage for people who meet certain medical criteria and low income guidelines
- 🌹 Apply for benefits at your local Social Security Office
- 🌹 CF diagnosis alone does not make a person eligible for benefits. A person applying for SSI or SSDI must meet certain medical criteria. Both SSI and SSDI have the same medical criteria
- 🌹 The application and approval process for SSI and SSDI can take months but will pay retroactively if approved
- 🌹 Many CF patients are initially denied and must seek legal counsel with appeal process

# SSI/SSDI cont'd

- The person has a certain FEV1 based on height
- The person has been hospitalized 3 times in the year prior to applying for benefits or has had episodes of bronchitis, pneumonia, or hemoptysis resulting in intervention by a physician 6 times in the past year
- The person has a persistent pulmonary infection requiring intravenous or nebulized antimicrobial use once every 6 months
- <http://www.ssa.gov/disability/professionals/bluebook/3.00-Respiratory-Adult.htm>
- <http://www.esiason.org/pdf/BEFSSAInformationSheet.pdf>
- *The Advocacy Manual: A Clinician's Guide to the Legal Rights of People with Cystic Fibrosis* is a book available for review at your CF Care Center and contains sample letters and additional information about Social Security medical criteria



# SDI (State Disability Insurance)

Short term disability benefit for California residents who are temporarily disabled (other states may have similar programs)

Pays a percentage of your income during disability period

SW can assist with application process

There is a 7 day “grace period” before benefits begin.

Expect 2-3 week time for your SDI to come through once approved

Larger companies (30+ employees) often have short and long term disability programs for employees

PLF also under this program (EDD)

# Legal resource

 <http://www.usacfa.org/attorneyframe.htm>

CF legal hotline is available to all CF patients and provides free information about the laws that protect the rights of individuals with CF

(800)622-0385/CFLegal@cfserv.com

Funded by CF Foundation and other grants

Administered by Beth Sufian who is an attorney and adult with CF

# Insurance

- 🌹 Insurance is a primary concern among adults with CF
- 🌹 Insurance is essential to health maintenance and must be followed and managed carefully
- 🌹 SW is not an insurance expert but can consult with patients about a variety of insurance concerns and refer patients to appropriate place for further information
- 🌹 Financial counselors available at SHC

# GHPP (Genetically Handicapped Person's Program)

- Insurance program in California for people with genetic diseases like CF
- Provides coverage for most aspects of CF care as well as primary care
- Participants must pay an annual fee based on income (0 up to 12,000); however there are no income requirements to be accepted into the program. Once the annual fee is paid, there is no cost for medical care
- Application process can take up to a year
- Program is understaffed and it is very difficult to get through on the phone
- Can work with other insurance programs including Medi-Cal, Medicare, and private insurance. Does not cover anything if person has an HMO
- Application is downloadable at the website:  
<http://www.dhcs.ca.gov/services/ghpp/Pages/default.aspx>
- (800)639-0597
- SW can provide education and advocacy for those applying for GHPP

# Living Breath Foundation

- 🌹 [www.thelivingbreathfoundation.org](http://www.thelivingbreathfoundation.org)
- 🌹 Provides financial grants, scholarships, and other benefits for CF patients
- 🌹 Donor funded
- 🌹 Gas cards for clinic patients
- 🌹 SW can assist with grant applications and offer gas cards when available

# Support group

- ❁ SW facilitates monthly support group for adult CF patients and their loved ones or caregivers
- ❁ First Friday of every month from 12 to 1pm at the Li Ka Shing Center for Learning, medical school campus
- ❁ Teleconference or Web Ex is available for those who cannot attend due to health concerns or distance from CF center
- ❁ Topics will focus on therapeutic healing and maintaining peace and balance while living with CF

# Therapy Services

- ✿ 30% adults with CF screened positive for depression; these results were closely related to lung function (Riekert et al, 2007)
- ✿ Professional literature indicates that rates of psychiatric disorders in the CF population do not differ significantly from those of the general population (Admi, 1996; Raymond, 2000)
- ✿ Seeking therapy is a sensible coping strategy for CF
- ✿ SW can refer CF patients for psychotherapy
- ✿ There are multiple options available in the community based on ability to pay, insurance coverage, and type of therapy desired, etc
- ✿ CF Quality of Life Program offers low cost counseling services to CF patients at the Community Center for Health and Wellness, 744 San Antonio Road, Suite 22/24, Palo Alto
- ✿ Therapy can be done via Skype or telephone  
(650)855-8898

# Transition Process

- 🌹 Transition from pediatric program to adult program is a significant milestone for a young adult with CF
- 🌹 Can be a time of anxiety, confusion, and disruption of care
- 🌹 SW provides counseling, collaboration, advocacy, and resource assistance to those who are going through transition



# Closing statements

- 🌹 CF patients are constantly adapting and adjusting to increasing complexity of care
- 🌹 SW strives to optimize the lives of those with CF using their strengths as a basis for intervention
- 🌹 Feedback always welcome
- 🌹 Questions???

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