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 02, 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 or 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.ssa.gov/disability/professionals/bluebook/3.00-Respiratory-Adult.htm)
- *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](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
- 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.
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 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
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???
References

- Burker EJ, Sedway J, Carone S. Psychological and educational factors: better predictors of work status than FEV1 in adults with cystic fibrosis. Pediatric Pulmonology 2004