Building a Survivorship Program

Regina Franco, NP MSN
Manager of Center for Integrative Oncology & Survivorship (CIOS)
Cancer Institute, Greenville Health System
The Cancer Institute of Greenville Health System

- 5 counties
- 10 sites of service
- 60 cancer specialists
- 500 employees
- Certified by the American College of Surgeons Commission on Cancer
Center for Integrative Oncology & Survivorship (CIOS)

Leadership

Larry Gluck MD, Medical Director GHS Cancer Program
Mark O’Rourke MD, Medical Director CIOS
Carla Jorgenson MD, Medical Director, Cancer Genetics
Gina Franco MSN, NP, Manager: CIOS, Genetics & Nurse Navigation

Staff

4 NPs, 2 Nurse Navigators, 2 Onc Rehab RNs,
1 Dietitian, 1 Social Worker, 1 Exercise Specialist,
1 Physical therapist, 1 Music Therapist,
3 Genetic Counselors and support/billing staff
Center for Integrative Oncology & Survivorship

- CIOS Established June 2012
- Cancer Support Community affiliate June 2012 (1st in US)
- Survivorship Care Plan Clinic started July 2012
- Oncology Rehab/Moving On started pre/post evaluations March 2013 (Moving On program started 1992)
- Psycho-social counseling started with social worker March 2013
- Gyn Oncology Survivorship Care Plan Clinic started April 2013
- Lifetime Clinic (LTC) started Nov 2013
- Human Performance Lab started seeing patients early 2014
- Lymphedema Management Program started April 2014
- Music Therapy Program started July 2014
Center for Integrative Oncology and Survivorship

- Survivorship
- Integrative Oncology
- Lifetime Clinic
- Oncology Rehab
- Psychosocial
- Music Therapy
- Nutrition
- Genetics
- Lymphedema Management
Center for Integrative Oncology & Survivorship (CIOS)
900 W. Faris Road, entrance 8 located on the 1st Floor
Phone: 864-455-1346 Fax: 864-455-5897
Download Referral Form: [www.ghs.org/cios](http://www.ghs.org/cios)
To refer in Mosaiq: go to referral tab-other-specific boxes for each service

<table>
<thead>
<tr>
<th>CIOS Departments</th>
<th>Current Services and Special Considerations</th>
</tr>
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</table>
| Survivorship Care Plan (SCP) Clinic | • One time multidisciplinary visit for all stages  
• Also a Survivorship Clinic specifically designed for GYN- Onc pts  
• Prostate CA- high risk surveillance also seen here  
• SCP’s provided to patient at completion of visit, includes path reports, referrals, and activities. |
| Genetics                  | • Consultations and follow up visits  
• Feel free to call regarding if referral is appropriate                                                   |
| Nutrition                 | • Free nutrition counseling and weight management program                                                  |
| Psychosocial              | • Psychosocial services (fee for service)  
• Cancer support Community Programs and support groups                                                      |
| Oncology Rehab            | • “Moving On” with GHS physician referral  
• Must be within 3 years of treatment, chemo/rad treatment must be completed. May be on maintenance therapy, labs must be normalized.  
• Must be able to exercise independently in a gym atmosphere                                                    |
| Smoking Cessation         | • Quit Smart Smoking Cessation Program  
• Pts receive NP eval with pharm management combined with other programs/therapies                          |
| Lifetime Clinic           | • Transition or a follow-up care to a NP led clinic  
• Must be stage 0-3-curate- post treatment                                                                     |
| Physical Therapy          | • Breast Cancer- lymphedema prevention and treatment  
• Free pre-surgical limb measurements                                                                          |
| Integrative Oncology      | • 30 minute consultation with oncology NP to answer any questions; includes eval, screening, & referral to any recommended CIOS services  
• Can make appointment for, during, or after treatments                                                            |
Survivorship ↔ Integrative Med

CIOS – mission of care:

CIOS platform - “integrative approach”

• Complementary therapies combined with conventional therapies to optimize health, minimize treatment side effects and promote overall healing

CIOS platform - “whole patient”

• Addressing the needs of the whole patient, not just their physical needs. Our survivorship professionals are experts at identifying each patient’s individual needs and connecting them to the right services

• Cancer is not a simple disease and survivorship care is about maximally healing each person through and after their treatments
Survivors: Are they as Good as New?
Listen to the patient......
...It’s not what we think......

“Whatever our wishes, the person who has come through a cancer experience is indelibly affected by it. The Humpty Dumpty idea of ‘as good as new’- a powerfully appealing notion for cancer patients- simply does not pertain. For better and for worse, physically and emotionally, the experience leaves an impression.”

Dr Mullans – Cancer Survivor
Survivorship Care Plans – Phase in 2015

Standard 3.3 - The cancer committee develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment. The process is monitored, evaluated, and presented at least annually to the cancer committee and documented in minutes.
All COC-accredited programs are required to provide SCPs to each patient at the end of each treatment by 2015.

Survivorship Care Plan components

– the care team;
– the background information, including the surgery and TNM stage;
– the treatment plan and summary, including the specific chemotherapy regimen with dates and the radiation therapy summary with dates; and
– the follow up care, including needs and concerns, as well as the schedule of follow up tests and visits.

**The Institute of Medicine’s Cancer Survivorship Care Planning Fact Sheet includes minimum plan standards.**
Key Recommendations:

1. All cancer stakeholders should work to raise awareness of cancer survivorship and to establish this as a distinct phase of cancer treatment.

2. Each patient should be given a Survivorship Care Plan reimbursed by insurers.

3. Plan components should be developed and refined using evidence-based clinical practice guidelines and assessment tools.

Considerations for Revision to CoC Standards

• **Driving force:** Institute of Medicine- “From Cancer Patient to Cancer Survivor: Lost in Transition” 2005

**Issues Identified by the Institute of Medicine**

- Patient centered care is not well implemented
- Systems can be complex and fragmented
- Patients excluded from care team and decision making
- Too much unwanted or unneeded care
Survivorship Careplan Clinic (SCP)
## Survivorship Care Planning (n=16)

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>Categories</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of Survivor Care Plan*</td>
<td>NCCN Survivor Care Plan</td>
<td>6%</td>
</tr>
<tr>
<td></td>
<td>Journey Forward</td>
<td>13%</td>
</tr>
<tr>
<td></td>
<td>LiveStrong Care Plan</td>
<td>6%</td>
</tr>
<tr>
<td></td>
<td>ASCO Treatment</td>
<td>0%</td>
</tr>
<tr>
<td></td>
<td>Plan/Summary</td>
<td>6%</td>
</tr>
<tr>
<td></td>
<td>Star Survivorship</td>
<td>6%</td>
</tr>
<tr>
<td></td>
<td>Cancer Center Developed</td>
<td>69%</td>
</tr>
<tr>
<td></td>
<td>None</td>
<td></td>
</tr>
<tr>
<td>Designated Survivor Care Planning Staff</td>
<td>Yes</td>
<td>19%</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>81%</td>
</tr>
</tbody>
</table>

* Percents do not equal 100% because respondents had option to check all that apply; 3 sites noted they will soon start utilizing a care plan and 2 plans were noted: ASCO Plan and Equicare Star Survivorship
Survivorship Visit Pathway

**Referral**
- Survivorship visit 1-3 mos. post treatment

**Preparation**
- Intake form sent to patient
- Abstract Treatment Summary
- Survivorship Plan

**Clinic Visit**
- Survivorship MD/NP

**Reports**
- EHR
- SCP Summary
Survivorship Office Visit Pathway

**Referral**
- Referral incoming – office nurses generate referrals in EHR when patient completes chemo, radiation, or after surgery
- Screening of referral reviewed to make sure appropriate and correct timing
- Other Visits: Int Onc Visit, Onc rehab, Lifetime Clinic

**Office Prep**
- Patient called to screen/need for Survivorship Program
- Questions answered
- Barriers assessed
- Appt made
- Data collect & SCP created

**SCP Appointment**
- Multi-Disciplinary Assessments & Recommendations by each MD/NP
- SCP explained and given to patient
- Nurse Navigator
- Dietitian
- Social Worker
- Referrals made:
  - F/U dietitian
  - F/U soc worker
  - Onc Rehab
  - Other services
  - Other screening
  - F/U plan reviewed

**Documents:**
- Progress note and SCP sent to PCP and in EHR for all onc team to see

**Patient returns to Onc team for F/U care**
Careplan Templates

Our NPs have collaborated with our nurse navigators to create at least 14 different types of survivorship careplans, examples follow:

<table>
<thead>
<tr>
<th>Breast</th>
<th>Colorectal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung</td>
<td>Prostate</td>
</tr>
<tr>
<td>Head and Neck</td>
<td>Hodgkin’s Lymphoma</td>
</tr>
</tbody>
</table>
| Non-Hodgkin’s Lymphoma | 4 Gynecology Templates  
(endometrial, vulva, cervical, ovarian) |
| 3 Dermatology Templates  
(basal, squamous, melanoma) | |
A survivorship care plan (SCP) visit occurs ideally when the patient is in remission after completing adjuvant therapy for a cancer, such as breast, colon, lung, etc or after completing curative therapy for lymphoma, etc.

- Survivorship Careplan presentation
- Distress screening/Evaluation of Needs
- Evaluation for Research Trials
- Nutrition consultation
- Education/Referral for ongoing programs and hospital/community resource
Survivorship Careplan Pearls

Time Savers
- Mail intake forms
- Phone call reminders (not automated)
- Place forms and referral forms on web page
- Multidisciplinary team – see patients separately

Careplan Delivery
- Encourage patients to share their SCP with their team
- Provide pathology reports to patients
- Survivor-centered care more effective than “top-down” care- self empowerment

Education
- “Teachable Moment”
- Alerts survivors to, and normalizes, the challenges of life after treatment
- Need programs
- Many national standards for svshp f/u disease and symptom (ASCO, NCCCP)

Screening & Assessment
- Skilled staff to find “unmet needs”
- Screen for distress
- Follow-up plan is still a challenge
- No “One Size Fits All”
- Nurse Navigators invaluable
Individual nutrition counseling is available at the MDC and/or CIOS from Jessica Menig. She addresses:

- undernourishment due to cancer treatment (especially pancreatic cancer surgery and ENT surgery and radiation therapy)
- unplanned weight change during and after cancer therapy
- healthy dietary habits for cancer survivors.
- Nutrition counseling available free of charge at any point during cancer treatment and aftercare.
Psychosocial Counseling

- Individual psychosocial (cognitive behavioral) counseling is available as a billable service
- A surprising number of patients with distress identified at their SCP have chosen to come back to see the social worker
- Programming for cancer support through the Cancer Support Community (CSC)
- Activities Calendar with several new groups available
- Local Resource Directory – available and distributed in CIOS
Lifetime Clinic
Options for Follow-up Care in Oncology

OPTIONS
For Follow-Up

- Traditional Follow-up with treating oncologists
- Blended Follow-up: Alternate Visits with Lifetime Clinic
- Complete Transition to Lifetime Clinic
NP lead clinics that will see patients and follow patients according to agreed algorithms/pathways and national standards.

Ultimately, the Lifetime Clinic may be able to assume follow up for many patients.

The providers will pay special attention to wellness issues, such as lifestyle, exercise, diet, bone health, screening for other cancers, genetic counseling, and cancer-specific symptoms.

A clinic exclusively for cancer survivors. This clinic would exist to see patients in surveillance after completion of initial and adjuvant therapy.
Lifetime Clinic-Pathway

Referral
- Med/Rad Onc in Mosaiq: Referral put on the LTC QCL for the navigator by CIOS scheduler
- Referrals outside of Mosaiq – are received via fax on paper. CIOS scheduler puts it on LTC QCL for the navigator to screen patient and schedule appt
- All referrals addressed by scheduler w/in 2 wks

Screening
- Nurse navigator checks to see if the patient is appropriate for LTC.
  - If DX < 3 years - SCP visit & SCP w/in 4-6 wks - If DX > 3 years see next appt date due.
  - Clear with other physicians to release to LTC (med onc, surg onc, rad onc) – cancel those appts
- Continue F/U with subspecialist for that respective cancer: GI surgeon, urologist, dermatologist, neurosurgeon

Patient Notification
- Patient notified via phone by nurse navigator within 2 weeks of referral: talking points covered, questions answered, appointment scheduled for SCP or LTC – whichever appropriate. (<3 years SCP visit, > 3 years LTC next appointment due.
- Packet mailed to patient: LTC letter, appointment date and time, directions to clinic, call LTC if problems arise
- ALERT button marked in Mosaiq. Document in MED. ONC notes section in Mosaiq or RAD MD notes section.

Prep & Visit
- If < 3 years prepare SCP. Appointment date within 4-6 weeks
- If DX 3 to 5 years – see pt. NEXT appropriate visit time with a modified abbreviated SCP provided on the day of the visit. No copies of path reports or radiation summary provided
- If DX > 5 years ago NO SCP for LTC visit UNLESS doctor ordered an SCP/LTC visit. Then an abbreviated care plan will be prepared and provided at SCP visit, followed by LTC visit.

Visit
- Assessment of unmet needs, distress, QOL, Svshp issues - H & P by NP,
- Dictation by NP
- Referrals any testing/labwork
- Return appt given
AYA refers to cancer survivors between ages 15 and 39.

Meets the special needs of this group for cancer surveillance, health maintenance, and cancer-specific symptoms and issues.

Survivorship clinic that transitions from the GHS Pediatric Oncology Program to an Adult Program.

Provides a seamless and comprehensive pediatric and adult cancer program.
Cancer Genetics Clinic

• 5-10% of all cancer cases due to inherited genetic change
• Three board certified genetic counselors onsite who gather family history and assess risk
• Counselors discuss genetic testing options with patient, then communicate and interpret results
• Positive mutations offered evaluation and counseling by medical oncologist and counselor
• Universal Lynch Screening started 10/1/14
Genetic Counseling Initial Visit

Screening
- Algorithms at MDC, CCC, and Breast Health Center for appropriate referrals
- Working on outreach to offices to increase awareness/referrals

Referral
- Referral Tabs for visits in Mosaic OR
- Form can be downloaded for outside offices

Intake forms
- Forms mailed to patient
- Personal medical history and hormonal history (for women)

Consult
- Cancer information
  - Risk based on history for 1) cancer and 2) hereditary cancer syndrome
  - Assess risk level and review options for testing as appropriate
  - Facilitate decision-making regarding testing
  - Facilitate testing if elected (blood draw or saliva sample)
Genetic Counseling Follow-up Visit

Scheduling

- Genetic Counselors screens all patients to determine whether or not testing is indicated
- Appointment made by genetic counselor upon disclosing positive results

Consult

- Medicare patients are seen by nurse practitioner and genetic counselor due to Medicare guidelines
- GC and Dr. Jorgensen meet with all patients that have positive results and review management, testing appropriate relatives, psychosocial adjustment
Oncology Rehab Programs
Physical Therapy & Lymphedema Management

*Complete Decongestive Treatment (CDT)*
Non-invasive, multi-component approach to effectively treat and manage lymphedema and related conditions including:

- Education
- Exercise
- Compression
- Skin Care
- Manual Lymph Drainage
Use of Perometers in PT

- We are one of the few hospitals in the country to have a perometer which is manufactured in Germany
- Lymphedema certified physical therapist uses a perometer for accurate limb measurement
- Allows for computer system to gather lymph fluid measurement just from the push of a button
- Creates more comfortable environment for patient and allows for more time during visit to treat patient
Oncology Rehab – Moving On Program

Program Details

- 12 week exercise program offered at GHS Life Center supervised by Rehab Nurse and two trainers
- Program is one hour meeting three times a week with four classes
- Detailed pre and post-assessments including body composition and physical exam

Program Requirements

- Must be within 3 years of the last chemotherapy or radiation therapy
- Open to all patients in remission or with stable disease able to go to a gym to exercise
- Ineligible if wheelchair bound or poor ECOG performance – (please refer directly to physical therapy)

Program Statistics

- 400 patients evaluated prior to entry to program
- 200 patients attend the 12 week Moving On program annually

**Lymphedema management – please refer directly to physical therapy**
Oncology Rehab- Moving On Pathway

Referral & Screening
- Referral Tabs in Mosaic
- Phone call to screen if appropriate

Questionnaire
- In office survey to screen health issues, medications, and lifestyles

Moving On Pre-Exam
- Nurse & NP visit
- Exam to screen
- TUG & 6 minute walk test
- Body Comp ordered

Moving On Program
- Exercise template is created for patient
- Pedometer is given to patient
- Life Center
- 12 weeks - 1 hour sessions 3 times a week
- Body comp repeated at program end

Moving On Post- Exam
- Nurse & NP visit
- Exit Exam
- Repeat 6 minute walk test
- Review & compare pre & post body comps
- Progress Report Card given to patient

Nutrition Counseling referral (If needed)

Physical Therapy referral (if needed)
USC School of Medicine Greenville
Exercise is Medicine
Collaborative Research with GHS Cancer Institute

There is a current epidemic of disease related to sedentary behavior making it imperative to train future physicians to understand the relationship between physical activity and health. The USC School of Medicine Greenville conducts investigator-initiated research as well as provides students opportunities to participate in leading, one-of-a-kind research with physicians and clinicians related to the benefits of exercise and medicine.

Moving on Oncology Rehabilitation Study in Cancer Survivors
Jennifer L. Trilk, Ph.D.
W. Larry Gluck, M.D.

Effects of Chemotherapy on Muscle Mitocondrial Oxidative Capacity in Breast Cancer Survivors
USCSOMG Third Year Medical Students
(Trilk, PI; Gluck Co-I)

Effects of Chemotherapy on Muscle Mitocondrial Oxidative Capacity in Pediatric Cancer Survivors
USCSOMG Second Year Medical Students
(Trilk, PI; Gluck Co-I)
Measuring the 4 Cornerstones of Physiological Health

- The USCSOMG Human Performance Lab’s state-of-the-art equipment helps GHS clinicians improve patient rehabilitation outcomes

**Cardiorespiratory Fitness**
- Maximal Rate of Oxygen Consumption ($VO_{2\text{max}}$)

**Metabolic Fitness**
- Lactate Threshold
- Muscle Mitochondrial Oxidative Capacity

**Muscular Strength**
- Maximal Power Output
- Maximal Strength

**Body Composition**
- Fat Free Mass/Lean muscle
- Fat Mass - Visceral Adipose Tissue
- Bone Mineral Density
Why Exercise for Cancer?

- Exercise decreases risk of many types of cancers and *may even be protective against progression of some cancers*
- Maintains or decreases weight, increases lean muscle mass and strength, increases cardiorespiratory and metabolic fitness, decreases risk of osteoporosis, improves fatigue, depression, and anxiety
Integrative Therapies
Music Therapy

• “Music Therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program.” –The American Music Therapy Association

• Music Therapy is the use of music to achieve non-musical goals.
Music Therapy Sessions:
Individual vs. Group

• Group music therapy sessions will have several different musical activities.
  – Activities may include lyric analysis, songwriting, playing small percussion instruments (such as shakers), singing, movement to music, passive music listening, and relaxation to music.

• Every individual music therapy session is different per individual.
  – An individual music therapy session begins with an assessment of the patient. Music activities are structured around the individual’s preferred music, daily goals and objectives, and, if applicable, long-term goals and objectives.
Music Therapy and Medicine

Music Therapy can assist in:

• Anxiety and stress reduction
• Non-pharmacological management of pain and discomfort
• Positive changes in mood and emotional states
• Active and positive patient participation in treatment
• Decreased length of stay
• Emotional intimacy with families and caregivers
Smoking Cessation Clinic - QuitSmart Model

- Quit Smart is a best practice model – Dr Robert Shipley – Duke University
  www.quitsmart.com
- Quit Smart Certification offered
- Evidenced based multi-disciplinary approach
- Systematic weaning of nicotine with use of other adjuvant meds and nicotine in a systematic process
- Additional support with SC DHEC’s Tobacco Quitline- ‘Quit for Keeps’
- 1-800-QUIT-NOW

A QuitSmart study found that 66% of their participants were still smoke free six months after quitting compared to 16-30% in other programs.
Smoking Cessation Program at GHS Cancer Institute

- The patient is provided with a guidebook, cigarette substitute and a relaxation CD
- Electronic referrals in EHR
- NP assessment in 4 office visits
- Program treats all members of household
- Nurse Navigator calls patient in between and after visits to track success/answer questions
- Low dose CT screening for patients that meet entry criteria
Mind-Body Programs

- Mindfulness meditation training at the CIOS:
  - Referral to community resources
  - Classes at CIOS

- Acupuncture
  - Referral to acupuncturists
  - National Cancer Institute Research at CIOS

- Massage available at the GHS Life Center

- Yoga classes available at the GHS Life Center and elsewhere.
Acupuncture and Massage

**Acupuncture** recommended as a complementary therapy:

- when pain is poorly controlled
- when side effects from other modalities are clinically significant
- when reducing the amount of pain medicine becomes a clinical goal
Massage Therapy

**Massage** can be safe during active treatment or in post-treatment survivorship care:

- when practiced by a skilled therapist with a background or training in massage and cancer
- must discuss precautions of massage with a qualified provider
- modifications might be required to work around side-effects or complications of radiation, chemotherapy, surgery, and medications
- modifications might be required for those with co-morbid conditions (e.g. rheumatoid arthritis, spine injuries, osteoporosis, or when cancer has spread to the bone).
CSC at GHS Cancer Institute

- We are the **first** collaborative hospital in the country with CSC
- Kick off began in February of 2013
- Programming was implemented March 2013
- Currently we have 200+ members
- We predicted those numbers to double by January 2014
CSC Programs

- **Comprehensive Support**: Enhancing well-being through support groups, one-to-one connections, and development of community
- **Education**: Empowering through classes, evidence based workshops and print materials
- **Social Activities**: Connecting and engaging with others in a supportive environment, learning new things and having fun
- **Healthy Living Programs**: Improving quality of life through stress reduction, movement, nutrition and mindfulness
Survivorship Clinic: Case Study of AK

- African American female, age 60 at diagnosis
- Stage IIIA breast cancer, long-term diabetic
- Mastectomy, reconstruction planned
- 6 cycles of chemotherapy
- Radiation
- Endocrine Therapy
Clinic Visit Assessment for AK

• Height 5’5”, weight 230 lbs, BMI 38.3
• Dependent on cane, difficulty with ADL
• Right arm and trunk lymphedema
• Fatigue level 9, pain level 4, distress inventory 44 (very high level of distress)

“I quit church when I was diagnosed, I stay at home all day, I don’t want anyone to see me like this”

“Dr. says it will take 4 surgeries to repair my breast. I hate my appearance! I’m bald, fat, and only have one breast now”

“I am a bother to you all, and I am not worth the time you all are giving me”
Clinic Interventions for AK

- Nurse navigator consults with NP and Social Worker
- Interdisciplinary visit for crisis intervention and counseling
- Referrals to lymphedema PT, dietitian and social worker
- Dietitian counsels AK
  - diabetic-appropriate diet
  - recommends Healthy Weigh Class at CIOS (3 sessions)
- Individual counseling with social worker (3 sessions)
- Lymphedema specialists helps with lymphedema management and education (6 sessions)
AK Progress after SCP Visit

- Actively participated in group nutrition classes and complying with nutritional counseling: “I have been using a calorie counting book with my daughter to record my food intake”
- Exercise: “I am using a stationary bike with my daughter”
- Referred to RCP for balance and gait training
- Referred to Brownell Center for evaluation, medication adjustment
- Poor body image and distress related to public appearance remain: “I don’t want to go back to church yet… I don’t want everyone asking where I’ve been and why I’m bald”
Survivor-Centered Care is Essential

Education Alone is NOT Enough – need programs

Programs -› need array
“One size does not fit all”

Need skilled multi-disciplinary team to make the Right Referrals for the Right Patient

Survivors are more likely to participate in their own care if they FEEL we are addressing their needs

Optimize a survivor’s ability to evaluate their own lifestyles and embrace healthy changes
Other Necessary Components

Time, Talent, Treasures

• Without the volunteers that have committed their time, patience, and heart to this program we wouldn’t be able to accomplish our goals
  – Often those volunteers can either lead us to philanthropic donors or become ones themselves
  – Even though these may not be billable employees they are huge market differentiators

• Sound leadership supports our requests of FTEs and budget