MY
CARE
NOTEBOOK

Create Your Own Care Plan for Teens

Included in this notebook are three forms designed to help you create your own care plan. You might choose to use one form - or all three. These forms were developed in collaboration with teens that have ongoing health needs. We tried to make these care plans as flexible as possible. You can use or change the forms to best meet your needs.

If this is your first time filling out a care plan, it may help you to work through these together with your parents and doctor.

- Getting to Know Me Provides space to write about your general health, strengths and challenges. A completed sample document is included.

- What's the Plan? Designed to help you organize your questions and concerns. Helps plan for doctor visits and includes space for writing down "next steps". A completed sample document is included.

- In Case of Emergency Provides information that would be critical to people caring for you in an emergency. It is designed so that you can carry it with you at all times in your wallet. A completed sample document is included.

Next steps: Think of people that you would like to share your care plan with. These may be people that help take care of your health or people that may need to know about your health. They could include doctors, nurses, therapists, teachers, coaches, friends, grandparents or neighbors.
Good luck!

Getting to Know Me

Name:	Nickname:
Date of Birth:	Today's Date:

Who am I? How would I describe myself?

What are my strengths/interests?

What is my life like in the community?
(Things to consider: school, favorite places)

How would I describe my family situation?
(Things to consider: siblings, parents, other relatives, pets, where you call home)

What is my diagnosis (diagnoses) and what that means for me?
(Things to consider: doctor's explanation, my explanation)

What are my challenges?
(Things to consider: things that frustrate me about my illness, how people interact with me due to my illness)

What do I think of my overall health?
(Things to consider: limitations, things that bother me, things I can control)

What are my prior surgeries, procedures, lab/diagnostic studies?

Date:	Procedure:	Results:

What are my current medicines/doses?

For additional copies of this form and more, please visit http://www.cshcn.org
Center
6/08

What are my allergies?

What are things to avoid? *(Things to consider: food, procedures, activities such as gym class, etc.)*

What Equipment/Assistive Technology do I need?
Braces/orthotics ☐ Walker, wheelchair ☐ Communication device ☐ Home O_2 ☐ Insulin pump ☐ Nebulizer ☐ Suction ☐ Other:

What other things I'd like you to know about me and my condition:

How do I want information: *(Things to consider: tell me in writing, tell me alone, or tell me and my parents together)*

Things I want help with:
Boundaries:

My responses to my illness: *(Things to consider: general responses, tired, excited, hungry)*

How I want to be treated:
☐ It's OK to ask me if I need help. ☐ It's **not** OK to ask me if I need help ☐ It's OK to ask me details about my condition ☐ It's **not** OK to ask me details about my condition

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Getting to Know Me

Name: Janet Doeman	**Nickname: Jane**
Date of Birth: 3-28-95	**Today's Date:** 6-5-08

Who am I? How would I describe myself?

I am a 13 year old girl who has a heart condition. I like to read, dance, cheerlead, swim, and hang out with my friends. I am a person who likes to have fun.

What are my strengths/interests?

I get really good grades in school. I like to dance and cheerlead, and I am on teams at school and at the park for this.

What is my life like in the community?
(Things to consider: school, favorite places)

I get good grades in school and have a lot of friends. I go to church with my parents every week and everyone there knows me. My favorite places to hang out are at the park, at the mall, or in my room with my friends.

How would I describe my family situation?
(Things to consider: siblings, parents, other relatives, pets, where you call home)

I have two brothers who live with me and my dad. My mom lives a few blocks away. We have two cats and a dog. If there are problems I can call my mom or my dad. My mom usually takes me to my doctors appointments.

What is my diagnosis (diagnoses) and what that means for me?
(Things to consider: doctor's explanation, my explanation)

I had two ventricular septal defects and a coarctation of the aorta that were repaired when I was a baby. Now I have mitral valve regurgitation.

I had two holes between the lower chambers of my heart and my main artery was pinched when I was born. They fixed this when I was a baby. Now I have a leaky valve.

What are my challenges?
(Things to consider: things that frustrate me about my illness, how people interact with me due to my illness)

I don't like it when people think that I won't be able to do things because of my heart condition. I also don't like it when I get tired earlier than other kids. Sometimes people treat me like I'm sick when I tell them about my illness, and I wish that they wouldn't.

What do I think of my overall health?
(Things to consider: limitations, things that bother me, things I can control)

I am pretty healthy. Sometimes I get tired more than other people, and I'm not allowed to run, but I can do almost everything else. It bothers me when people tell me I can't do something before I've tried. I am allowed to try anything and if I think its too much then I can stop.

What are my prior surgeries, procedures, lab/diagnostic studies?

Date:	Procedure:	Results:
1993	Open Heart Surgery	Fixed coarctation of the aorta
1994	Open Heart Surgery	Patched the holes of my VSD
2005	Cardiac Catheterization	I have a mitral valve that leaks

What are my current medicines/doses?

No medication right now.

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What are my allergies?
Codeine - I stop breathing Ceclor - I get a rash

What are things to avoid? *(Things to consider: food, procedures, activities such as gym class, etc.)*
No blood or blood pressure from my left arm. I'm not allowed to run.

What Equipment/Assistive Technology do I need?
Braces/orthotics ☐ Walker, wheelchair ☐ Communication device ☐ Home O_2 ☐ Insulin pump ☐ Nebulizer ☐ Suction ☐ Other: None right now

What other things I'd like you to know about me and my condition:
Nothing that I can think of.

How do I want information: *(Things to consider: tell me in writing, tell me alone, or tell me and my parents together)*
I want you to tell me if something is wrong so we can plan for it. If something is really scary I want you to wait for my mom to get there to tell me.

Things I want help with:
Sometimes I need you to explain things more than once so that I can understand it. Using pictures helps.
Boundaries: I don't want help when I'm trying to see if I can do something. Don't tell me I can't dance unless I've tried it and I know I can't.

My responses to my illness: *(Things to consider: general responses, tired, excited, hungry)*
When I have worked too hard I get tired and I have to rest. When I'm really tired I get upset and sometimes I yell at people if they won't leave me alone.

How I want to be treated:
☒ It's OK to ask me if I need help. ☐ It's **not** OK to ask me if I need help ☒ It's OK to ask me details about my condition ☐ It's **not** OK to ask me details about my condition

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What's the Plan?

Name:	Date of Birth:	Provider:
Parent's Name:		Today's Date:

What do I want to talk about today?

Specifics today
- What's new?
- How have I been feeling?
- Worries down the road?
- What am I planning before the next visit or in the near future?

What do I hope to have happen?

- Today
- From the doctor
- For me to do

Next steps? What needs to be done?

- Labs
- Change medicine
- Check insurance

Who will do this?

- Me
- Parents
- Doctors
- Nurse

By when? (time frame)

- Immediate
- 1 month
- 6 months
- 1 year

If I think of anything else later, who do I call?

- Questions
- New appointments
- Email Addresses

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Washington State Department of Health

What's the Plan?

Name: Janet Doeman	Date of Birth: 3-28-93	Provider: Dr. Heart
Parent's Name: Mary and John		Today's Date: 6-12-08

What do I want to talk about today?	
Specifics today • What's new? • How have I been feeling? • Worries down the road? • What am I planning before the next visit or in the near future?	I have been feeling more tired lately and wonder if something is wrong. I want to know if I will need any more surgeries soon or if I need to start taking medicine again. I am planning on going to stay with my grandparents for a week in Wisconsin and want to know if that is ok.
What do I hope to have happen?	
• Today • From the doctor • For me to do	I hope that the doctor tells me that everything is fine and that I don't need to do anything. If something is wrong, I hope that they can give me some medicine to make me feel better but that I don't have to stay in the hospital.
Next steps? What needs to be done?	
• Labs • Change medicine • Check insurance	Do I need to start taking medicine again? Do we have to do more tests? When is my next appointment? Should I be keeping a log of when I feel tired like before? What are the worst things this could be and how would we fix those?
Who will do this?	
• Me • Parents • Doctors • Nurse	Will dr. give me prescription? Can mom make my next appt? Can I check in with my nurse practitioner if I don't feel good?
By when? (time frame)	
• Immediate • 1 month • 6 months • 1 year	Can we know why I'm more tired before cheerleading season starts? Can I still go to visit my grandparents? If we need to do anything more, can we do it so I don't miss school?
If I think of anything else later, who do I call?	
• Questions • New appointments • Email addresses	Who should I call? Nurse practitioner?

Emergency Information for:

Name: ______________________________

Today's Date (mm/dd/yy): ________________

Birth Date (mm/dd/yy): __________________

Primary Language: _____________________

Address: ______________________________

Parents/Guardians | Phone Numbers

____________________ H: ________ W: ________ C: ________

____________________ H: ________ W: ________ C: ________

Diagnosis

Diagnosis:

Medications: Dose Time

Allergies:

Emergency Contact – Relationship/Phone#

Doctor's Information

Main Doctor: ______________________
Phone: __________ Fax: __________

Specialty Doctor: ___________________
Phone: __________ Fax: __________

Specialty Doctor: ___________________
Phone: __________ Fax: __________

Hospital: __________________________
Phone: __________ ER: __________

Pharmacy: _________________________
Phone: __________

Insurance:

Most Important Things to Know About Me in an Emergency

Copies of this form are available at http://cshcn.org

Directions:

1. Fill in and/or print form
2. If you have Acrobat Reader 8.0 or higher, you may save this PDF for future edits (visit Adobe's site to download the newest version of Acrobat Reader)
3. Cut on heavy dashed lines
4. Fold on dotted lines to fit in wallet

Emergency Information for:

Name: ______________________

Today's Date (mm/dd/yy): ______________

Birth Date (mm/dd/yy): ______________

Primary Language: ______________

Address: ______________________

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Parents/Guardians	Phone Numbers
______________	H: ________
	W: ________
	C: ________
______________	H: ________
	W: ________
	C: ________

Diagnosis

Diagnosis:

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Medications:	Dose	Time

Allergies:

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Emergency Contact – Relationship/Phone#

____

Doctor's Information

Main Doctor: ______________________

Phone: ____________ Fax: ____________

Specialty Doctor: ______________________

Phone: ____________ Fax: ____________

Specialty Doctor: ______________________

Phone: ____________ Fax: ____________

Hospital: ______________________

Phone: ____________ ER: ____________

Pharmacy: ______________________

Phone: ____________

Insurance:

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Most Important Things to Know About Me in an Emergency

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Washington State Department of Health

Hospital Name

Address: ____

City, State, Zip Code: ____________________ Website: ____________________

Phone Numbers:

Main Number: ____________________ Emergency Room: ____________________

Medical Record Number: ______________________________________

- Clinic: ____________________ Hours/Days of Operation: ____________

  Physician: ______________________________________

  Contact Person / Title: ______________________________

  Phone: ____________ Fax: ____________ Email: ____________________

- Clinic: ____________________ Hours/Days of Operation: ____________

  Physician: ______________________________________

  Contact Person / Title: ______________________________

  Phone: ____________ Fax: ____________ Email: ____________________

- Clinic: ____________________ Hours/Days of Operation: ____________

  Physician: ______________________________________

  Contact Person / Title: ______________________________

  Phone: ____________ Fax: ____________ Email: ____________________

Medical / Dental
Community Health Care Providers

- Primary / Community Care Provider: ______________________________

Office Nurse: ______________________________

Address: ______________________________

Phone: ____________ Fax: ____________ Email: ____________

Website: ______________________________

- Community Hospital: ______________________________

Medical Record Number: ______________________________

Address: ______________________________

Phone: ____________ Fax: ____________ Email: ____________

Website: ______________________________

- Community Specialty Care Provider: ______________________________

Address: ______________________________

Phone: ____________ Fax: ____________ Email: ____________

Website: ______________________________

- Community Specialty Care Provider: ______________________________

Address: ______________________________

Phone: ____________ Fax: ____________ Email: ____________

Website: ______________________________

- Dentist / Orthodontist: ______________________________

Address: ______________________________

Phone: ____________ Fax: ____________ Email: ____________

Website: ______________________________

Home Care
Community Health Care / Service Providers

- Home Nursing Agency: ______________________________

Start Date: ______________________________

Contact Person: ______________________________

Address: ______________________________

Phone: ____________ Fax: ____________ Email: ______________

Website: ______________________________

- Home Nursing Agency: ______________________________

Start Date: ______________________________

Contact Person: ______________________________

Address: ______________________________

Phone: ____________ Fax: ____________ Email: ______________

Website: ______________________________

- Home Nursing Agency: ______________________________

Start Date: ______________________________

Contact Person: ______________________________

Address: ______________________________

Phone: ____________ Fax: ____________ Email: ______________

Website: ______________________________

Therapists
Community Health Care / Service Providers

Therapists:

- Occupational Therapist (OT) ______________________________

Start Date: ______________

Agency: ______________________________

Address: ______________________________

Phone: __________ Fax: __________ Email: ______________

- Physical Therapist (PT): ______________________________

Start Date: ______________

Agency: ______________________________

Address: ______________________________

Phone: __________ Fax: __________ Email: ______________

- Speech-Language Pathologist: ______________________________

Start Date: ______________

Agency: ______________________________

Address: ______________________________

Phone: __________ Fax: __________ Email: ______________

Pharmacy
Community Health Care / Service Providers

• Pharmacy: ______________________________ Hours/Days of Operation: __________________

Contact Person: ____

Address: ____

Phone: ___________________ Fax: _________________ Email: ___________________________

Website: ____

• Pharmacy: ______________________________ Hours/Days of Operation: __________________

Contact Person: ____

Address: ____

Phone: ___________________ Fax: _________________ Email: ___________________________

Website: ____

• Pharmacy: ______________________________ Hours/Days of Operation: __________________

Contact Person: ____

Address: ____

Phone: ___________________ Fax: _________________ Email: ___________________________

Website: ____

Special Transportation
Community Health Care / Service Providers

- Transportation (to and from medical / therapy appointments)

Contact Person: ____________________

Agency: ____________________

Address: ____________________

Phone: __________ Fax: __________ Email: __________

Website: ____________________

- Transportation (to and from medical / therapy appointments)

Contact Person: ____________________

Agency: ____________________

Address: ____________________

Phone: __________ Fax: __________ Email: __________

Website: ____________________

Family Information

- Your Name: ________________________ Nickname: ________________________
  Date of Birth: __________________________________
  Diagnosis: ____
  Blood Type: __________________________________
  Legal Guardian: ____
  Address: ____
  Phone: ______________________________________

Family Members

- Mother's Name: ____
  Address: _______________________________ Email: _________________________
  Daytime Phone:______________ Evening Phone:______________ Cell: ______________
- Father's Name: ____
  Address: _______________________________ Email: _________________________
  Daytime Phone:______________ Evening Phone:______________ Cell: ______________
- Sibling's Name: ______________ Age: _____ Name: ______________ Age: _____
  Name: ______________ Age: _____ Name: ______________ Age: _____
- Other Household Members: ____
- Important Family Information: ____
- Language Spoken at Home: ________________________
  Other Language(s): ______________________________
  Interpreter Needed? Yes: ☐ No: ☐
  Interpreter: ___________________________________ Phone: ______________

Emergency Contact

- Name: ____
  Address: _______________________________ Email: _________________________
  Daytime Phone:______________ Evening Phone:______________ Cell: ______________

Insurance/Funding Sources

- Insurance Company: ___
  Policy Number: ___
  Contact Person / Title: ___
  Address: ___
  Phone: ___ Fax: ___ Email: ___
  Website: ___

- Insurance Company: ___
  Policy Number: ___
  Contact Person / Title: ___
  Address: ___
  Phone: ___ Fax: ___ Email: ___
  Website: ___

- Insurance Company: ___
  Policy Number: ___
  Contact Person / Title: ___
  Address: ___
  Phone: ___ Fax: ___ Email: ___
  Website: ___

- Supplemental Security Income (SSI): ___
  Contact Person / Title: ___
  Address: ___
  Phone: ___ Fax: ___ Email: ___
  Website: ___

(continued)

Insurance/Funding Sources

- Other: ______________________________

  Contact Person/Title: ______________________________

  Address: ______________________________

  Phone: __________ Fax: __________ Email: __________

  Website: ______________________________

- Other: ______________________________

  Contact Person/Title: ______________________________

  Address: ______________________________

  Phone: __________ Fax: __________ Email: __________

  Website: ______________________________

Care Schedule

TIME	CARE
Morning	
Afternoon	

Care Schedule

TIME	CARE
Evening	
Night	

Appointment Log

DATE	PROVIDER	REASON FOR APPOINTMENT / CARE PROVIDED	NEXT APPOINTMENT

Medical / Surgical Procedures

DATE	PROCEDURE	RESULTS	COMMENTS

Lab Work / Tests / Procedures

DATE	TEST	RESULTS	COMMENTS

Equipment / Supplies

- Name of Equipment: ______________________________

  Description (brand name, model, size, etc.): ______________________________

Date obtained: ____________ Supplier: ______________________

Website: ______________________________

Contact Person: ______________________ Phone: ______________

Serial Number: ______________________________

- Name of Equipment: ______________________________

  Description (brand name, model, size, etc.): ______________________________

Date obtained: ____________ Supplier: ______________________

Website: ______________________________

Contact Person: ______________________ Phone: ______________

Serial Number: ______________________________

- Name of Equipment: ______________________________

  Description (brand name, model, size, etc.): ______________________________

Date obtained: ____________ Supplier: ______________________

Website: ______________________________

Contact Person: ______________________ Phone: ______________

Serial Number: ______________________________

- Name of Equipment: ______________________________

  Description (brand name, model, size, etc.): ______________________________

Date obtained: ____________ Supplier: ______________________

Website: ______________________________

Contact Person: ______________________ Phone: ______________

Serial Number: ______________________________

Medications

Allergies:

Pharmacy: Phone:

MEDICATION	DATE STARTED	DATE STOPPED	DOSE / ROUTE (with or without food?)	TIME GIVEN	PRESCRIBED BY

Diet Tracking Form

DATE	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
Tube Feeding							
Breakfast							
Lunch							
Dinner							
Snacks							
Notes							

Hospital Stay Tracking Form

DATE	HOSPITAL	REASON	NOTES

Medical Bill Tracking Form

DATE	PROVIDER	COST	INSURANCE PAID	DATE PAID	FAMILY OWES	DATE PAID

"MAKE-A-CALENDAR" Month Year

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

Notes

Getting to Know Me

Name:	Nickname:
Date of Birth:	Today's Date:

Who am I? How would I describe myself?
What are my strengths/interests?
What is my life like in the community? *(Things to consider: school, favorite places)*
How would I describe my family situation? *(Things to consider: siblings, parents, other relatives, pets, where you call home)*
What is my diagnosis (diagnoses) and what that means for me? *(Things to consider: doctor's explanation, my explanation)*
What are my challenges? *(Things to consider: things that frustrate me about my illness, how people interact with me due to my illness)*
What do I think of my overall health? *(Things to consider: limitations, things that bother me, things I can control)*
What are my prior surgeries, procedures, lab/diagnostic studies?
Date: Procedure: Results:
What are my current medicines/doses?

For additional copies of this form and more, please visit http://www.cshcn.org

What are my allergies?

What are things to avoid? *(Things to consider: food, procedures, activities such as gym class, etc.)*

What Equipment/Assistive Technology do I need?
Braces/orthotics ☐ Walker, wheelchair ☐ Communication device ☐ Home O_2 ☐ Insulin pump ☐ Nebulizer ☐ Suction ☐ Other:

What other things I'd like you to know about me and my condition:

How do I want information: *(Things to consider: tell me in writing, tell me alone, or tell me and my parents together)*

Things I want help with:
Boundaries:

My responses to my illness: *(Things to consider: general responses, tired, excited, hungry)*

How I want to be treated:
☐ It's OK to ask me if I need help. ☐ It's **not** OK to ask me if I need help ☐ It's OK to ask me details about my condition ☐ It's **not** OK to ask me details about my condition

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Emergency Information for:

Name: ______________________

Today's Date (mm/dd/yy): ______________

Birth Date (mm/dd/yy): ______________

Primary Language: ______________

Address: ______________________

Parents/Guardians — Phone Numbers

______________ H: ________ W: ________ C: ________

______________ H: ________ W: ________ C: ________

Diagnosis

Diagnosis: ______________________

Medications: Dose Time

Allergies: ______________________

Emergency Contact – Relationship/Phone#

____

Doctor's Information

Main Doctor: ______________
Phone: ________ Fax: ________

Specialty Doctor: ______________
Phone: ________ Fax: ________

Specialty Doctor: ______________
Phone: ________ Fax: ________

Hospital: ______________
Phone: ________ ER: ________

Pharmacy: ______________
Phone: ________

Insurance: ______________________

Most Important Things to Know About Me in an Emergency

____

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3. Cut on heavy dashed lines
4. Fold on dotted lines to fit in wallet

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Washington State Department of Health

What's the Plan?

Name:	**Date of Birth:**	**Provider:**
Parent's Name:		**Today's Date:**

What do I want to talk about today?

Specifics today
- What's new?
- How have I been feeling?
- Worries down the road?
- What am I planning before the next visit or in the near future?

What do I hope to have happen?

- Today
- From the doctor
- For me to do

Next steps? What needs to be done?

- Labs
- Change medicine
- Check insurance

Who will do this?

- Me
- Parents
- Doctors
- Nurse

By when? (time frame)

- Immediate
- 1 month
- 6 months
- 1 year

If I think of anything else later, who do I call?

- Questions
- New appointments
- Email Addresses

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Washington State Department of Health

Got Transition

http://www.gottransition.org/youth-information

"What Does This Have to Do With Me?"

As you get older, YOU will begin to make choices that will affect your health. Here at Got Transition we hope to support you to make those choices carefully. We want to provide you with information, tools, connections to other youth, and also people who work in the health care systems - so that they will understand the things you are scared or worried about.

It is the hope of the team at Got Transition that when you feel supported, involved and empowered in your own health care, you will be more likely to have a positive transition experience!

"How can I learn more?"

There are lots of things that Got Transition is doing to make sure you are interested and maybe even exciting about health care transition!

- ❑ Find us on Facebook! On our Facebook page you will get to see the latest webinars, Got Transition events, and lots of resources and articles about what's going on with health care transition. https://www.facebook.com/HealthCareTransition
- ❑ Follow us on Twitter!
- ❑ Check out our page of resources with information about everything from how to talk to your doctor to learning about being a self advocate. http://www.gottransition.org/youth-resources
- ❑ Sign up for the Got Transition E-news so you can hear about all upcoming events and things that might interest you! http://www.gottransition.org/get-e-news

Healthcare Transition Plan for Teens

Each person will have a unique journey in their transition from pediatric to adult healthcare. Part I of this worksheet will help you start thinking about common concerns and issues you may need to consider. Then use Part II to come up with specific healthcare transition goals with the help of your doctor and/or parents. You can track to-do items to see how much progress you've made!

Name:	**Today's Date:**
PART I	
Topics to Consider	**Issues/Concerns**
How will I manage my own health condition?	
How will I manage my own medication/equipment/supplies?	
How will I manage my own financial issues/insurance plan?	
How will I become an active decision-maker for my own health?	
How might my health condition impact my relationships with others?	
What services will I need as an adult, and who will provide them?	
What are my education plans after high school?	
What are my employment plans?	
What are my plans for independent living, housing, transportation, and recreation?	

Goal examples could include: Find three new potential adult care doctors, research available insurance plans, or gather documentation such as medical records or care plans.

PART II						
Today's Date	**Goal**	**Action(s) Needed**	**Who is Responsible**	**Target Date**	**Date Complete**	**Next Steps**